



## **Embodying Investigations of Cerebral Palsy A Case of Open Cognitive Science**

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**PhD Thesis**  
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**Embodying Investigations of Cerebral Palsy**  
**A Case of Open Cognitive Science**

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Submitted: 29/06/15

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**Title:** Embodying Investigations of Cerebral Palsy:  
A Case of Open Cognitive Science

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*“I believe that when science and art thus join hands the most commanding motive for human action will be reached; the most genuine springs of human conduct aroused and the best service that human nature is capable of guaranteed.”*

John Dewey

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## Abstract in English

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The main question of this Ph.D dissertation is: *how do we help persons living with cerebral palsy (CP)?* In order to give an answer to such a complex and challenging question, it is first of all necessary to answer another essential question: *what does it mean for a person to live with CP?* An all-encompassing understanding of CP is presented as a way to answer this question. Such an understanding requires that one takes up a so-called ‘bio-psycho-social’ perspective on CP.

The dissertation turns to the so-called E-approaches to cognition for investigating the biological, psychological and social aspects of living with CP. The claim of *embodying cognition*, which is a pragmatic claim that, as cognitive scientists ‘we should do as we say’, is described and endorsed. Since we argue that the mind is embodied, embedded, enacted and extended, we should, as minded scientists, be embodying these considerations in the methods and ways of studying cognition. For the case of CP, this means that we need to ‘open up’ cognitive science so as to be able to embody and embed the investigation in the world of CP, and engage and collaborate with persons with CP, with their relatives and with professionals that work with CP.

In Part I of the dissertation, a phenomenologically-inspired method for opening up cognitive science is developed. It’s argued that open cognitive science is not just a question of interdisciplinary research or open access publishing, but of being ‘open-minded’. This requires a change in mindset regarding how one does science, how one understands collaboration and communication, and how one understands the way in which society and science are of mutual relevance. In order to use such open method specifically for the case of CP, a framework of phenomenological interview is developed and discussed.

In Part II, the results of such a method are presented in relation to CP and to aspects of neuro-physiological and computational (bio), psychological and social import. The issues discussed are those of: 1) the experience of disability, 2) motor control and sense of agency, 3) sense of control and bodily certainty, and 4) of collaboration in the case of helping. The aim is to understand the experiences of how the persons are able to live with CP, so as to take those experiences as a point of departure for helping them.

Based on this theoretical work, Part III develops an embodied-based model of intervention for CP, focusing on the experience of self-control as a way to help people with CP. In addition, a theatre performance, *Humane Liquidation*, and a documentary film, *Natural Disorder*, are developed so as to both communicate what it means to live with CP and empower persons with CP, their families and friends, as well as people for whom such insights might be of relevance.

All these scientific, therapeutic and artistic initiatives are developed and integrated since, there is only one way forth in order to answer such complex and challenging questions about what it means to live with CP and how we can help persons to do so: *We need to open up and collaborate.*

## Abstract in Danish

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Hovedspørgsmålet i denne Ph.D. afhandling er: *Hvordan hjælper vi personer, der lever med cerebral parese (CP)?* For at give et svar på et sådant komplekst og udfordrende spørgsmål, er det først og fremmest nødvendigt at besvare et andet afgørende spørgsmål: *Hvad betyder det for en person at leve med CP?* En helhedsorienteret forståelse af CP præsenteres som indgangsvinklen til at besvare dette spørgsmål. Sådant en forståelse kræver, at man anvender et såkaldt "bio-psyko-socialt" perspektiv på CP.

Afhandlingen anvender de såkaldte E-tilgange til kognition for at undersøge de biologiske, psykologiske og sociale aspekter af det at leve med CP. Påstanden om det at *kropsforankre kognition* er beskrevet og accepteret, hvilket er en pragmatisk påstand om, at som kognitionsforskere 'skal vi gøre, som vi siger'. Da vi argumenterer for, at bevidsthed er kropsforankret, indlejret, handlet og ekstenderet, bør vi, som bevidste forskere, kropsforankre disse overvejelser i vores metode at studere kognition på. Det betyder i forhold til CP, at vi er nødt til at åbne kognitionsvidenskaben, således at vi er i stand til at kropsforankre og indlejre undersøgelsen i CP-verdenen, og medinddrage og samarbejde med personerne med CP, deres pårørende og de professioner, der arbejder med CP.

I afhandlingens Del I udvikles en fænomenologisk inspireret tilgang til at åbne kognitionsvidenskaben. Der argumenteres for, at åben kognitionsvidenskab ikke kun er et spørgsmål om tværfaglig forskning eller frit tilgængelige udgivelser, men om at være 'åben tænkende.' Dette kræver en ændring i ens tankegang om, hvordan man bedriver videnskab, hvordan man forstår samarbejde og kommunikation, og hvordan man forstår den måde, som samfundet og videnskaben er af gensidig relevans. For at kunne bruge sådan en åben metode specielt i forhold til CP, udvikles og diskuteres en model for fænomenologisk interview.

I del II præsenteres resultaterne af denne åbne metode i forhold til CP og med fokus på aspekter af neuro-fysiologisk (bio), psykologisk og social karakter. De emner, der diskuteres, er: 1) oplevelsen af handicap, 2) motorkontrol og følelsen af handlingskraft, 3) følelsen af kontrol og kropslig sikkerhed, og 4) det at samarbejde i forhold til at hjælpe. Formålet er at forstå personernes erfaring i at leve med CP og at anvende disse erfaringer som udgangspunkt for at hjælpe dem.

På baggrund af dette teoretiske arbejde udvikles der i Del III en kropsforankringsbaseret interventionsmodel for CP. Her er der fokus på oplevelsen af selvkontrol som en måde at hjælpe folk med CP. Derudover udvikles en teaterforestilling, *Human Afvikling*, og en dokumentarfilm, *Naturens Uorden*, med det formål at kommunikere, hvad det vil sige at leve med CP, og at 'empower' personer med CP, deres pårørende, samt mennesker for hvilke, sådanne indsigter kan være relevante.

Alle disse videnskabelige, terapeutiske og kunstneriske tiltag udvikles og integreres, fordi der er kun én vej frem for at besvare sådanne komplekse og udfordrende spørgsmål om, hvad det vil sige at leve med CP, og hvordan vi hjælper personerne med at gøre: *Vi er nødt til at åbne op og samarbejde.*



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# Chapter 1

## Introduction

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As an umbrella term, Cerebral Palsy (CP) is defined as a group of disorders affecting the development of postural and motor control and occurring as a result of a non-progressive lesion in the developing central nervous system, causing activity limitation (Bax et al. 2005; Rosenbaum et al. 2007). In 90% of the cases, the lesion occurs during pregnancy and, contrary to a common belief, isn't the result of difficult delivery, prematurity or neonatal asphyxia (Ellenberg & Nelson 2013). This makes CP the most common type of disorder associated with lifelong motor impairment (Aisen et al. 2011). Currently, 3-4 individuals per 1000 of the general population have CP (Yeargin-Allsopp et al. 2008), and it's expected to appear in 2 neonates per 1000 live births worldwide (Bax et al. 2007).

At the same time, CP is a heterogeneous condition that varies according to the particular brain lesion and individual in question. As a result, CP is typically classified according to its different types of motor symptoms (spastic, dyskinetic, or ataxic) and to the bodily location of the motor impairment (mono-, hemi-, para-, and tetraplegia). Spasticity is seen in most cases of CP, where the lesion affects the upper motor neurons, damaging the motor neurons' ability to regulate descending motor pathways and resulting in muscular overactivity (e.g. exaggerated tendon reflexes and hypertonia) (Dietz & Sinkjaer 2007; Sheean & McGuire 2009).

This dissertation will focus on spastic CP, which means that, whenever the notion of 'CP' is used, it refers to 'spastic CP,' if not otherwise specified. Since CP is in most cases a congenital disorder, the main question is: *how do we help persons living with CP?* This question is as complex and difficult to answer as any healthcare question, and the aim of the dissertation is not to give a conclusive answer to the question. The aim is to give specific, yet limited, answers to how we can help people to live with CP by focusing primarily on the experience of control and certainty in living with CP. In order to do so, it's essential as a point of departure to focus on another question, namely: *what does it mean for a person to live with CP?* If we are to be able to help persons with CP, one way or another, we must first of all understand what we need to help them with.

### 1. The Limits of the Antispasticity Focus

The notion of 'spasticity' comes from the Latin *spasmus*, which means a sudden and violent muscular contraction with a convulsive and painful character. More recent definitions of spasticity define it in terms of either the 'hyper-excitability of the stretch reflexes' (Lance 1981) or the 'intermittent or sustained involuntary activation of muscles' (Pandyan et al. 2005). The current trend in research and clinical practices

for CP is invested in developing and optimizing antispasticity treatment protocols (Pandyan et al. 2005). These antispasticity protocols work under the assumption that there is an implicit, yet unproven, causal relationship between the neuro-physiological disorder (spasticity) and the activity limitations, participation restrictions and reduced personal independence that all are part of CP (Barnes 2001, see also Rosenbaum et al. 2007).

Despite extensive work on these neuro-physiological aspects, the clinical impact on activity, participation and independence is still limited (Sheean 2001, Pandyan et al. 2005). One reason is that we need to improve research in both spasticity and antispasticity clinical practice, but another reason, as will be made evident in this dissertation, is that we need to broaden our understanding of what it means to live with CP.

The notions of ‘activity’, ‘participation’ and ‘independence’ used above come from the International Classification of Functioning, Disability and Health (ICF) (ICF 2001). This classification system embodies a conceptualization of disability that is grounded in a notion of ‘human functioning’ that has the experience of human functioning at its core. This refers to an experience that cuts across 1) biological health conditions and bodily impairments, 2) psychological and personal factors of, for example, activity, self-esteem and motivation, and 3) social and environmental factors that influence participation, such as complex social, cultural and political climates. Thus, in order to understand what it means for an individual person to live with disability within an ICF framework, we need to operate with an all-encompassing ‘bio-psycho-social’ model (WHO 2011, 4), where disability is a complex and dynamic interaction between these three aspects of impairment, activity and participation. The overall aim is to treat “disability as a continuum rather than categorizing people with disabilities as a separate group: disability is a matter of more or less, not yes or no” (WHO 2011, 5).

## **1.1. Experiential, Psychological and Social Aspects of CP**

In relation to the case of CP, this means that the spasticity focus is necessary but not sufficient and that we need to broaden our understanding of CP in order to include its experiential, psychological and social aspects. Freud was in fact the first to develop the classification system of CP that is still used today, though with minor revisions (Panteliadis et al. 2013), and he emphasized that CP is not only a matter of motor impairment, but also of issues of sensation, cognition, communication, perception and behavior (Freud 1897).

These aspects are also included in recent definitions of CP, such as in Rosenbaum et al. (2007), and recent research does suggest that, depending on the location, extent, and temporal development of the lesion, CP additionally includes deficits in proprioception (Lee et al. 1990; Riquelme & Montoya 2010), perceptuo-motor functioning (van der Weel et al. 1996), cross-modal mapping of vision and proprioception (Wann 1991), spatial tactile discrimination (Sanger & Kukke 2007), and joint-position sense and kinesthesia

(Wingert et al. 2009). However, only a few studies have discussed the experiential, psychological, and social implications of living with CP.

Such studies have primarily focused on children with CP and identified increased barriers and problems in social participation and peer relations in comparison to healthy children (see Imms 2008 and Bottcher 2010 for review). A recent study looking at the body image of adolescents with CP suggests that they are less disposed to physical training than their ‘normal’ peers and more apt to regard their bodies as unreliable, dependent on help from others and likely to catch other people’s attention (Hammar et al. 2009). Only a modest number of studies have previously investigated the first-person experiences of adults living with CP (e.g. Sandström 2007; Peckitt et al. 2013).

A broad and all-encompassing understanding of CP is absent in current CP research, but how should one develop such a ‘bio-psycho-social’ model for investigating what it means to live with CP?

## **2. Embodied Cognitive Science**

In this dissertation, I will turn to cognitive science in order to find inspiration for developing such a ‘bio-psycho-social’ model of investigating CP. In the last couple of decades, cognitive science has undergone a reformation. So-called embodied, embedded, enacted and extended (E) approaches to cognition have joined forces as an alternative to traditional cognitive science. The latter may go by different names, primarily by Cognitivism, but is criticized for focusing solely on explanations that read cognition in mental terms and situate it within the skull. By contrast, the new E-approaches hold different fundamental claims, which stress that cognition is not only skull-bound.

Cognition is embodied—it depends on the cognizer’s embodiment (Clark 1997; Wilson 2002; Gallagher 2005; Chemero 2009; Shapiro 2011)—and enactive—it depends on the cognizing organism’s activity (Varela et al. 1991; Hurley 1998; Noë 2004; Thompson 2007). Cognition is embedded—it depends on the cognizer’s relation to the natural and social environment (Haugland 1998; Clark 1997; Hurley 1998)—and can be extended—it depends on vehicles beyond the cognizing organism (Clark & Chalmers 1998; Clark 2008). Thus, in including biological, bodily, contextual and technological aspects of cognition, the E-approaches seem to be a relevant framework for investigating the biological, psychological and social aspects of living with CP.

From being an alternative, a buzz and a trend in cognitive science, the E-approaches to cognition have become increasingly influential (Ward & Stapleton 2012). Scholars are currently referring to them as a new science of the mind (Rowlands 2010) or a new paradigm of cognitive science (Stewart et al. 2014). Nevertheless, it would be a mistake to characterize them as a rigidly defined and unified research program for cognitive science. Grouped together, the embodied, embedded, enacted and extended approaches to

cognition suffer from internal disagreements over fundamental issues, such as subject matter, methodological commitment and the definition of central notions such as ‘embodiment’. There is no homogeneity, and even the conclusion that these approaches unite through a shared enemy is also too strong (Menary 2010). Weak modifications in contrast to radical rejections of traditional cognitive science coincide with grouping together the different approaches. Thus, the explanatory capacity and success of this new paradigm of cognitive science depends on further clarification.

This clarification is not going to be the aim of the dissertation, which is rather about understanding what it means to live with CP in order to help persons living with CP. Thus, the dissertation takes as its point of departure the claim that it’s not sufficient to understand cognition in whatever neuronal, mental or computational terms that would restrict cognition to the skull. Mind, body and world should be seen here as mutually dependent in an account of cognition.

## **2.1. The Experience of Living with Pathology**

Another claim, which is not explicitly justified in the dissertation, is that a complete science of cognition needs to address, or at least be able to account for, the experiential aspects of cognition. This means that subjectivity, consciousness and yet another E, namely emotion (affect), should be part of cognitive science. This claim is typically advocated by phenomenologically inspired approaches to cognitive science, which emphasize the lived, ordinary and everyday experiences of the cognizer (e.g. Varela et al. 1991; Gallagher 2005; Ratcliffe 2008; Gallagher & Zahavi 2008, Thompson 2007, 2014; Collombetti 2014). The experiential aspects of cognition are continuously disregarded in the E-approaches, as for instance in Shapiro (2011) (see Martiny 2011 for a review), but the dissertation accepts the claim that, if we truly want to develop an embodied, enacted, embedded and extended cognitive science, we must acknowledge lived experiences as a constitutive part of cognition.

Thus, the claims that cognition is not skull-bound and that lived experience is a constitutive aspect of cognition are taken as the dissertation’s points of departure, while traditional discussions related to topics such as ‘representational vs. anti-representational’ aspects of cognition are left aside. Instead, as we will see, the justification of these claims is primarily indirect, pragmatic and related to the case of CP: if we embody these claims when trying to investigate what it means to live with CP, what, then, are the possibilities for cognitive science?

The use of pathologies, such as CP, is a fundamental part of cognitive science. However, in Cole’s review of Gallagher and Zahavi’s book *The Phenomenological Mind*, he raises concerns as to how pathology is incorporated into phenomenological analysis in the cognitive sciences (Cole 2008). First of all, phenomenologists tend to choose pathologies (e.g. schizophrenia and autism) that already lend themselves to phenomenological analysis and discussion, disregarding other less fashionable pathologies, such as, for

example, CP. Secondly, phenomenologists use the cases as part of their arguments, although there's no clear scientific understanding of the cases. Thirdly, people with pathology typically don't address topics interesting for phenomenological study, such as pre-reflective self-awareness, but rather talk about issues that are meaningful for them and for their daily life. Fourth, pathologies are typically understood in phenomenology as abnormalities, losses and deficits, but this is a somewhat narrow-minded focus, since part of the wonder is how people adapt and develop according to their pathology. This should also be part of the phenomenological analysis (Cole 2008, 30-32).

Cole criticizes Gallagher and Zahavi for having a top-down view of pathology and encourages them to get their hands dirty and 'take some walks' in the places that people actually live (Cole 2008, 32). However, being a cognitive scientist whose research deals with pathology, phenomenologically inspired or not, means more than getting one's hands dirty and actually meeting the persons one is trying to investigate. In studying persons with pathology, the question is more one of opening up one's research, questions, methods and theory so as to be able to engage with the persons one is studying and see the relevance that such scientific knowledge might bear for them.

Recent attempts to do so can be seen in for example the study of autism (Björne 2007; Robledo et al. 2012; de Jaegher 2013; Donnellan et al. 2013), which tries to reverse our theoretical glasses and pay attention to what persons with autism can do, what their possibilities of action are and how they describe them, rather than getting caught up in describing abnormalities and deficits suitable for driving theoretical research in cognitive science. How should we describe such an overall framework for engaging with pathologies in cognitive science?

### **3. A Pragmatic Mindset**

In the philosophical tradition of phenomenology, phenomenologists such as Husserl and Merleau-Ponty acknowledged that, if we are to be able to rigorously deal with the subjective aspects of experience, we need to accept that, scientists or not, the knowledge we have of the world is anchored in our own subjective perspective on the world. As scientists, we are also embodied and embedded subjects and, instead of seeing this subjective influence as problematic, the phenomenological method was developed so as to account for the subjective experience of minded subjects (Husserl 1970; Merleau-Ponty 1962).

In investigating subjects with pathology, we therefore need to be aware of our own subjective perspective on the matter, since this is just as much a possible source of error as any other error in experiment, measurement or research. Yet, how do we account for the subjective perspective while still conducting a scientific investigation, namely without succumbing to our own arbitrary, personal and contingent factors?

### 3.1. A Second-Person Method

Inspired by phenomenological considerations and discussions, Varela et al. emphasized in their pioneering work, *The Embodied Mind*, that there is an intrinsic circularity in cognitive science, since the study of cognition is always done by a cognizing subject. However, part of Varela et al.'s original contribution to dealing with this circularity has been overlooked in cognitive science, since the focus has mainly been on their appraisal of interdisciplinary methodology.

When dealing with the aspect of subjectivity in current cognitive science, the focus is typically on the methodological tension between phenomenology and science, that is, between first-person vs. third-person perspectives and data, and on ways of overcoming this tension by bridging the two through mutual constraints. This can for example be seen in the project of naturalizing phenomenology and, while this project is definitely part of the solution, Varela et al. (1991) in fact argued that, if we want to tackle the problem of subjectivity in science and understand the mind in embodied, enacted and embedded terms, a new pragmatics for doing cognitive science is required.

For Varela et al., the question of pragmatics — where pragmatism signifies the implementation of techniques, means and know-how, and refers to how well something adapts to its situation (Depraz et al. 2003, 17) — is an integral part of embodied cognitive science. In our case of CP, this refers to the knowledge of how to investigate what it means to live with CP, where the success criteria for knowledge is to understand *what it actually means for people to live with CP* – not what discussions in cognitive science claim it means.

The issue of pragmatics in cognitive science was further developed in Varela's research programme into neuro-phenomenology (Varela 1996), which is interesting in relation to the case of CP, since CP in part is caused by a brain damage, and we want to understand what this damage means for, and how it's experienced by, the person living with it. At the time when the research programme was introduced, cognitive science was showing limited interest in and motivation for including subjective reports of first-person experiences in its research and experimental settings. Subjective reports were and to a large extent still are, taken as scientifically problematic, since subjects can for instance be mistaken, biased, inaccurate and unreliable when giving their reports (Nisbett & Wilson 1977). In our case, one might question whether persons with CP are actually the best at knowing what it means to live with CP.

Varela not only argued that first-person experiences and their expression in subjective reports are necessary for cognitive science, i.e. that a mutual constraint exists between first-person and third-person methods in validating both subjective reports and empirical data, but also hinted at how this should be done pragmatically. As the techniques and methods of brain imaging become more and more sophisticated, we also need more and more sophisticated ways of drawing phenomenological discriminations and descriptions

of the phenomena we aim to study. Empirical questions should be guided by first-person knowledge, and this is an “important philosophical issue but it is also a pragmatic, empirical need” (Varela 1996, 341).

This requires first of all that a rigorous first-person method and procedure for exploring, analyzing and validating subjective reports is developed. In order for the subjects, in this case persons with CP, to give precise descriptions of their experiences, they cannot simply rely on uncritical introspection, a ‘just-take-a-look’ procedure. A science of consciousness is needed (Varela 1996). In Varela and Shear (1999), this scientific first-person method was developed into a *second-person method* where the role of a skilled mediator was seen as necessary in assisting the subjects to give precise subjective reports. The question in our case would be how ‘we can’ help people with CP understand and give descriptions of what it means to live with CP.

In current discussions in social cognition, this idea of a second-person method has been adopted by the so-called ‘interactive turn’ as a way to study people in an engaged way (e.g. de Bruin et al 2012; Schilbach et al. 2013; Satne & Roepstorff 2015). Interpersonal commitment, experiential engagement, and reciprocal and dynamic interaction are seen as crucial to this second-person study. In other words, we need to engage with the persons with CP in order to understand what it means to live with CP. Yet, where are the pragmatics and know-how of actually doing this second-person study? How should we investigate what it means to live with CP in the world where persons with CP actually live?

To incorporate pragmatic knowledge into cognitive science may, to some at least, seem reasonable, but it’s not at all an easy task. Gallagher and Marcel have argued, by pointing to Donaldson (1978), that the academic and analytic attitude that is the goal of western schooling detaches the scientist from his determination by worldly and pragmatic context. Qua scientists, we are of course embedded in a social scientific setting, and we embody and enact the rules of conduct for this setting, but the questions, methods, and answers of cognitive science are to a great extent disembodied and decontextualized (Gallagher & Marcel 1999, 287).

The same critique, yet stated a bit harsher, was presented over three decades ago by Neisser, who criticized the discussions on social cognition for being mainly observational and detached from the social world. He suggested that scientists could benefit from looking at other professions, such as theater, for inspiration, since the expertise of such professions consists in manipulating social impressions. According to Neisser, the reason why this isn’t done is that academics don’t take notice of professional accomplishments outside the university, since such professions lack the necessary scientific controls for illuminating issues on social cognition. For Neisser, this opinion means that academics are typically more interested in theoretical issues and concepts in social cognition than in the actual social phenomena (Neisser 1980).

My suggestion is that cognitive science needs to start appreciating that knowledge comes in different forms —e.g. ‘practical knowledge’, ‘know-how’, ‘experience’, ‘expertise’ and ‘tacit knowledge’—and that



it's essential to pay heed to these 'how' forms of knowledge when studying cognition. This pragmatic 'know-how' of understanding and investigating cognition is in fact flourishing in many other areas than in disciplines of cognitive science alone. Many professions having to do with human practice and interaction, such as education, sports training, therapy, medicine, art, and the Buddhist practice of mindfulness meditation, have expert knowledge on the matter. The latter was emphasized by Varela et al. (1991) as a way for cognitive scientists to become better at studying the mind, and has now become the foundation for Contemplative Science, which some call a new era for mind studies (Deborges & Negi 2013).

The point being made here is that cognitive science shouldn't only progress theoretically or have an interdisciplinary focus when developing a second-person study of cognition. We should in fact cultivate a new pragmatic mindset for doing cognitive science. This means that, in our case of CP, we need to 'open up' cognitive science so as to be able to engage and collaborate with persons with CP, with their relatives, and with professionals that work with CP, such as physio- and occupational therapists, psychologists, doctors, and so on.

## 4. Embodying Cognition

In order to open up cognitive science, the pragmatic focus requires a radical transformation in the mindset of doing cognitive science. This Varela clearly stated in relation to his method of 'neuro-phenomenology':

"My proposal implies that every good student of cognitive science who is *also* interested in issues at the level of mental experience, must inescapably attain a level of mastery in phenomenological examination in order to work seriously with first-person accounts. But this can only happen when the entire community adjusts itself - with a corresponding change of attitude in relation to acceptable forms of argument, refereeing standards and editorial policies in major scientific journals - so that this added competence becomes an important dimension for a young researcher. To the long-standing tradition of objectivist science this sounds anathema, and it is. But this is not a betrayal of science: it is a necessary extension and complement. Science and experience constrain and modify each other as in a dance. This is where the potential for transformation lies. It is also the key for the difficulties this position has found within the scientific community. It requires us to leave behind a certain image of how science is done, and to question a style of training in science which is part of the very fabric of our cultural identity." (Varela 1996, 347)

Varela stresses that there is a methodological tension between experience and science, which can be bridged through a dance of mutual constraints. Yet, this bridging can only succeed when the style and values of the 'objective' research community are themselves transformed. The 'hard' problem of consciousness is

therefore pragmatic and cultural: 1) to develop the pragmatics, tools and methods of cognitive science and 2) to change the habits in science so as to accept and cultivate them (ibid).

## 4.1 The Embodying Claim

The claim that is defended in this dissertation by means of engaging with the case of CP deals with these two issues of pragmatics and cultivation in doing embodied cognitive science. I call this claim *Embodying Cognition*.<sup>1</sup> It is a pragmatic claim that, as cognitive scientists, ‘we should do as we say.’ If we argue that the mind is embodied, embedded, enacted and extended, we should, as minded scientists, be embodying these considerations in the method and ways of studying cognition. In phenomenologically inspired terminology, it means that, when studying cognition, we should go from focusing exclusively on the reflective and detached ‘I think’ to a more pre-reflective, engaging and worldly ‘we can.’ In the case of CP, it means that, together, ‘we can’ understand what it means to live with CP.

This is not a strong methodological claim—it doesn’t point out a necessary inconsistency in embodied approaches that don’t embody their method—and it’s not a normative claim—it doesn’t stress that the best way to conduct embodied cognitive science is to embody cognition. Whether or not one should buy the claim of embodying cognition depends on the topic of cognition one investigates, the kinds of problems one aims to solve and the answers one hopes to give. However, if one wants to study and understand persons living with pathology, and especially if the aim is to help them, one needs to embody the embodied, embedded, enacted and extended considerations in one’s scientific practice. This point was in fact part of Cole’s critique of Gallagher and Zahavi, as presented above (Cole 2008, 30).<sup>2</sup>

## 4.2. How to Evaluate?

The evaluation of this dissertation should therefore be two-fold and should consist in the success, efficacy, and functionality of how well the developed pragmatics adapts both to the world of CP and to that of embodied, enacted, embedded and extended cognitive science. The former refers to the understanding of CP and the development of ideas, concepts, strategies and technologies for therapy, intervention and habilitation. The latter refers to what this research project contributes to the embodied paradigm of cognitive science. What new insights has the scientific work coming from this cognitive science project added to current debates and discussions about crucial topics of embodiment, agency, social cognition, etc.?

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<sup>1</sup> The change from the passive tense in *embodied* cognition, i.e. cognition should be understood as embodied, to the active tense in *embodying* cognition illustrates that, not only should cognition be understood as embodied, but that, when studying cognition, minded scientists should ensure that this fact is reflected in their practice.

<sup>2</sup> It should be mentioned that the original suggested title for *The Phenomenological Mind*, was in fact *Open Minds* (personal conversation with Zahavi). As it will be argued, the ability to ‘open up the mind’ is an essential part of embodying cognition.

This kind of evaluation is pragmatic in that it focuses on pinpointing the innovation, development and contribution that comes from this project within both the world of CP and that of cognitive science.

### 4.3. The Structure of the Dissertation

The structure of the dissertation is divided into three parts. Part I concerns the issue of opening up cognitive science so as to be able to understand what it means to live with CP. The discussions are therefore methodological. Chapter 2 further develops the claim of embodying cognition, as presented here in the introduction (chapter 1), by discussing the claim in relation to the recent Open MIND project in cognitive science and to the open science movement in general. Chapter 3 describes one way of framing a second-person study of cognitive science by developing a methodological framework called the phenomenological interview. By engaging in such interviews, it's possible to take the experience of living with CP seriously and use it as a point of departure for further investigation.

Part II presents the descriptions that persons living with CP provided when interviewed about their experience. Chapter 4 frames these descriptions in relation to studies of disability in order to present what can be called a phenomenological model of disability. This is done by using the case of CP to expand upon the current phenomenological account of illness in such a way as to be able to account for how people learn to attune to their disability. This requires an understanding of the notion of 'embodiment' from a 'bio-psycho-social' perspective. The next three chapters then further investigate the biological, psychological and social aspects of living with CP, with an explicit focus on how persons with CP have learned to live with CP.

In chapter 5, the biological aspect of living with CP is represented in connection with neuro-physiological and computational discussions of motor control in the sense of agency (SoA) debates. Here, two recent models for understanding motor control and Bayesian certainty in SoA are discussed in relation to how persons with CP experience SoA. In chapter 6, the psychological aspect of living with CP is represented in connection with the experience of control and certainty discussed in both psychologically and phenomenologically inspired cognitive science. Here, the aim is to understand how persons with CP acquire a sense of bodily certainty, despite their motor control disorder. In chapter 7, the social aspect of living with CP is represented in connection with discussions in social cognition that understand and describe the phenomenon of helping in the case of CP as being an act of collaboration. Since this chapter has a social focus, the descriptions from the interviews with persons with CP are correlated with descriptions from interviews with 'normal' persons about how they experience engaging with persons with CP.

All the interviews and work presented in part II were done at the Helene Elsass Center (HEC), a Danish habilitation center working primarily with CP. These results became the scientific and theoretical foundation for Part III, which concerns the relevance that this investigation has for the world of CP, as well as for embodied cognition. Chapter 8 presents a pilot-study of an embodied cognitive intervention for the

habilitation of CP and focuses on how to enhance the experience of self-control in CP. This intervention was developed in close collaboration with the staff at HEC, particularly those staff members working in occupational therapy, psychology, sports science, and pedagogics.

In chapter 9, the focus is extended from a habilitation perspective to a perspective of whether or not it's possible to investigate, and thereby change, how society understands CP. This requires the ability to communicate to others what it means to live with CP. To do so, the chapter presents an open experiment in second-person social engagement in which a theatre performance, *Humane Liquidation* (Human Afvikling in Danish), is used as a way to both communicate and change the social understanding of CP.

Somewhat the same agenda is at stake in chapter 10, where the documentary film *Natural Disorder* is discussed as a way to communicate what it means to live with CP. This is done in order not only to empower people living with CP, the relatives of those living with CP and others with a relation to the world of CP, but also to empower people for whom such insights might be of relevance. At the same time, the documentary film is an experiment in open media, which is a way of using a different, more embodied, embedded and enacted medium than the written one for doing and communicating science.

All the work and chapters presented in this dissertation are an attempt to open up cognitive science in order to investigate CP, an attempt that itself constitutes an overall experiment in the possibilities and constraints of embodying cognitive science.

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# Part I

## Opening up Cognitive Science

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## Chapter 2

# Embodying Cognitive Science: How to be Open-Minded

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# Embodying Cognitive Science: How to be Open-Minded

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## 1. Introduction

The Open Science (OS) movement has now made a substantial entry into cognitive science. This is especially seen with the newly launched Open MIND (OM) project, which is a collective experiment in open access publishing in cognitive science. This idea of opening up the minds of scientists isn't new, but is a fundamental premise in phenomenologically inspired Embodied Cognition (EC)<sup>3</sup> that is typically overlooked in cognitive science. This premise I call *Embodying Cognition*, which is a pragmatic claim that as cognitive scientists 'we should do as we say.'<sup>4</sup> If we argue that the mind is embodied, embedded, enacted and extended, we should, as minded scientists, be embodying these considerations in the method and ways of studying cognition.

This is not a strong methodological claim, pointing out a necessary inconsistency in embodied approaches that don't embody their method, and it's not a normative claim, stressing that the best way to conduct embodied cognitive science is to embody cognition. Whether or not one should buy the claim of embodying cognition depends upon what kind of topic of cognition that one is investigating, what kind of problems one aim to solve and the answers one hope to give. However, if one wants to open up the minds of cognitive scientists the claim is highly relevant.

The claim of embodying cognition is presented and discussed in this paper in relation to OM and OS, where the overall argument is that interdisciplinary collaboration, open access, or the engagement of science with society aren't in themselves sufficient solutions for being open-minded. Open-mindedness requires a change in mindset regarding how one does science, how one understands collaboration and communication, and how one understand the way in which society and science are of mutual relevance and import to one another, all of which are a matter of illustrating the relevance of academic endeavours.

## 2. The Open MIND Project

In their editorial paper to the OM project, Metzinger and Windt describe the notion of 'open-mindedness' as an epistemic practice and attitude for approaching ideas, topics, theories, methods, and fellow researchers.

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<sup>3</sup> I will use the term Embodied Cognition (EC) as a broad term that encompasses the other E-aspects of embedded, enacted and extended cognition.

<sup>4</sup> The change from the passive tense in *embodied* cognition, i.e. cognition should be understood as embodied, to the active tense in *embodying* cognition illustrates that, not only should cognition be understood as embodied, but that, when studying cognition, minded scientists should ensure that this fact is reflected in practice.

It's characterized by 1) epistemic humility, 2) intellectual honesty and 3) charity (Metzinger & Windt 2015, 2), which taken together highlight a pragmatic dimension of doing cognitive science: there should be no single and right way to do research, and the aim should be to ask better questions, to question or reject prior commitments, to see ambiguity and the possibility of falsification as indicators of great scientific process, and to promote new and sustainable forms of collaboration.

OM is promoting openness in cognitive science for the same reasons OS is promoting it in science in general. They are both referring to new and innovative ways of doing science, which should be seen in contrast to current scientific practice (Nielsen 2012; Metzinger & Windt 2015). In support of the need for such a new science, it's stated that we need to collaborate with and be open to the 'wisdom of the crowd' so as to efficiently restructure research in cognitive science (Metzinger & Windt 2015, 4) and broaden the range of problems that we can collaboratively solve together (Nielsen 2012).

Collaboration has become the talk of the town, even in the current scientific community (Adams 2013), but both OM and OS present inherent problems within the current system as an *ex negative* argument for a new way of doing science. These problems are primarily related to 'publish or perish' incentives, which result in exaggerated and inflated knowledge (Young et al., 2008), and in publications that need retraction (van Noorden 2011; Metzinger & Windt 2015). In addition, the peer review process is slow (Metzinger & Windt 2015), stifles innovation, and lacks transparency (Smith 2010; Nielsen 2012). Typically, publications don't include information necessary for the reproducibility of results (Knorr-Cetina 1981), and the exponential growth of publications creates an overload of information, leading to simultaneous and repeated discoveries and 'invisible colleges' (Price 1963).

Metzinger and Windt's theoretical solution for developing a new cognitive science is to discuss the phenomenology of open-mindedness, since they suspect that the cultivation of relevant kinds of phenomenal states and epistemic feelings will facilitate the development of such a new research climate (Metzinger & Windt 2015, 5). They acknowledge the problem of subjectivity and accept that the mind is an embodied and culturally embedded phenomenon (Metzinger & Windt 2015, 16). However, when it comes to their practical solution for cultivating open-minded science, none of these theoretical considerations are included, and the answer for OM is to publish research by open access. Typically, open access is also the practical solution when scientists in the OS are trying to do science in a new way.

However, Metzinger and Wind stress that the open MIND project is both the beginning of a conversation on how an open-minded attitude can be cultivated in cognitive science and an invitation for further development of the matter (Metzinger & Windt 2015, 2). I support OM's overall attempt to open up our minds, and accept this invitation, but what is required in order to cultivate open-minded science is a change of mindset, in which open access is just one part of a bigger picture. The aim here is to continue the conversation by painting larger parts of this picture.

### 3. Cultivating a New Mindset

In the philosophical tradition of phenomenology, the idea of doing science in a new way whereby one acknowledges that scientists are embodied and embedded subjects, was seen as necessary for dealing with the problem of subjectivity. Phenomenologists such as Husserl and Merleau-Ponty emphasized that the knowledge that we as scientists have of the world is anchored in our own subjective perspective on, and experience of, the world. Instead of seeing this subjective influence as problematic, the phenomenological method was precisely developed so as to account for the subjective experience of minded subjects (Husserl 1970; Merleau-Ponty 1962).<sup>5</sup>

Inspired by these phenomenological considerations and discussions, Varela et al. emphasize in their pioneering work, *The Embodied Mind*, that there is an intrinsic circularity in cognitive science, since the study of cognition is always done by a cognizing subject. Part of Varela et al.'s original contribution has, nevertheless, been overlooked in cognitive science, since the focus has mainly been on their appraisal of interdisciplinary methods.<sup>6</sup> For Varela et al., pragmatics are an integral part of embodied cognitive science, where the notion of 'pragmatism' can be defined as the implementation of techniques, means and know-how, and refers to how well something adapts to its situation (Depraz et al. 2003, 17). If we want to tackle the problem of subjectivity in science and understand the mind in embodied, enacted and embedded terms, know-how is required.

However, in order for this to be possible, such a pragmatic focus requires a radical transformation of the mindset of doing cognitive science, which Varela clearly states in relation to his method of 'neuro-phenomenology':

"My proposal implies that every good student of cognitive science who is *also* interested in issues at the level of mental experience, must inescapably attain a level of mastery in phenomenological examination in order to work seriously with first-person accounts. But this can only happen when the entire community adjusts itself - with a corresponding change of attitude in relation to acceptable forms of argument, refereeing standards and editorial policies in major scientific journals - so that this added competence becomes an important dimension for a young researcher. To the long-standing tradition of objectivist science this sounds anathema, and it is. But this is not a betrayal of science: it is a necessary extension and complement. Science and experience constrain and modify each other as in a dance. This is where the potential for transformation lies. It is also the key for the difficulties this position has found within the scientific community. It requires us to leave behind a certain image of how science is

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<sup>5</sup> To be clear, giving an account of subjective experience is not the same as giving a subjective account of experience (Gallagher & Zahavi 2008, 19).

<sup>6</sup> Many fundamental phenomenological ideas are surprisingly still disregarded when it comes to embodied cognition, as for instance in Shapiro 2011 (see Martiny 2011 for a review).

done, and to question a style of training in science which is part of the very fabric of our cultural identity.” (Varela 1996, 347)

Varela stresses that there is a methodological tension between phenomenology and science, which can be bridged through a dance of mutual constraints, as the project of naturalizing phenomenology demonstrates. Yet, this bridging can only succeed when the style and values of the ‘objective’ research community are themselves transformed. The ‘hard’ problem of consciousness is therefore pragmatic and cultural: 1) to develop the pragmatics, tools and methods of cognitive science and 2) to change the habits in science so as to accept and cultivate them (ibid).<sup>7</sup>

Problems with the current culture and mindset in cognitive science have also been emphasized by other phenomenologically inspired scholars such as Gallagher and Marcel. They argue, by pointing to Donaldson (1978), that the academic and analytic attitude that is the goal of western schooling detaches the scientist from his determination by worldly and pragmatic context. Qua being a scientist, we are of course embedded in a social scientific setting, and we embody and enact the rules of conduct for this setting, but the questions, methods, and answers of cognitive science are nevertheless to a great extent disembodied and decontextualized (Gallagher & Marcel 1999, 287). If we for example want to understand socially contextualized cognition and behavior, it’s problematic to do so by setting up questions and experiments that from the very beginning are detached from the social world and focus on abstract cognitive and behavioral components (ibid).

While, similar to the OM project, the solution presented in this paper is to open up the minds of cognitive scientists, the way to do so differs from that of OM. The aim here is to *embody* cognitive science, which means incorporating the theoretical considerations of ‘embodiment,’ ‘embedddness,’ ‘enaction,’ and ‘extension’ as an integral part of the method for studying cognition. In phenomenologically inspired terminology, it means that, when studying cognition and schooling cognitive scientists, we should go from focusing exclusively on the reflective and detached ‘I think’ to a more pre-reflective, active and worldly ‘we can’.

This is a pragmatic claim for doing cognitive science that will now be discussed in relation to three fundamental aspects for both open-minded cognitive science and open science: 1) collaboration, 2) communication, and 3) science and society.

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<sup>7</sup> For further discussion of the relation between traditional phenomenology and a new open science of the mind, see Depraz 2012 and Depraz & Cosmelli 2013.

## 4. Open-Minded Collaboration

Metzinger and Windt highlight, as it's now more or less custom to do in cognitive science, that the mind is embodied and embedded in a social cultural world but, when they discuss how to be 'open-minded' scientists, they argue that it is about breaking down demarcations between disciplines in cognitive science (Metzinger & Windt 2015, 4) and promoting interdisciplinary collaboration between scientists from different cultures, periods and age groups (Metzinger & Windt 2015, 20). While this is definitely part of the solution, it's not sufficiently embedded. If the mind is embodied and embedded in a social cultural world, we shouldn't restrict ourselves to scientific disciplines as such, but should include this world in our open-minded practice. This is also a fundamental point in OS, namely that knowledge isn't only to be found in academia.

The pragmatic 'know-how' of understanding the mind is flourishing in many other places than in different disciplines of science alone. Many professions having to do with human practice and interaction, such as education, sports training, therapy, medicine, art, and the Buddhist practice of mindfulness meditation, have expert knowledge on the matter. The latter was emphasized by Varela et al. (1991) as a way for cognitive scientists to become better at studying the mind, and has now become the foundation for so-called Contemplative Science, which some call a new era for mind studies (Desbordes & Negi 2013).

In open-minded science, we need to appreciate that knowledge comes in different forms and that it is essential to pay heed to the 'how' form of knowledge, such as 'practical knowledge', 'know-how', 'experience', 'expertise' and 'tacit knowledge,' when studying the mind. Metzinger and Windt acknowledge this and point out that wisdom is not only knowing how to live, but doing so as well (Metzinger & Windt 2015, 16; see also Ryan 2014; Russell 1912).

### 4.1. Experimenting with Collaboration: Theatre in Cognitive Science

The problem is, nevertheless, that opening up the research process to the 'wisdom of the crowd' doesn't automatically lead to better scientific knowledge, since there are many counterproductive examples where the crowd isn't wise. The challenge for cognitive science is therefore to harness the potential of being open-minded without 'openwashing' the necessary conditions for knowledge. We need knowledge of how to collaborate open-mindedly and, in order to acquire that, we not only need to think about and discuss how to do it, but we need to do it.

The solution is to open up cognitive science so as to be able to collaborate, when relevant and necessary, with partners outside academia that have specific knowledge in a certain area. Inspired by Neisser's (1980) interesting proposal that scientists studying social cognition could benefit from looking at professions in the

theater for inspiration, Martiny et al. (in progress)<sup>8</sup> conduct a collaborative experiment between EC and theatre, where theatre performance is used as part of a second-person study of social cognition.

The result of this experiment shows that multiple methods in cognitive science, including making use of theatre performances, developing engaging questionnaires, and performing phenomenological interview (see Høffding & Martiny forthcoming)<sup>9</sup> for a clarification of this interview form), offer promising ways to perform second-person studies of social cognition. Not only have both phenomenological interviews and the use of other methods been seen in other ‘open-minded’ experiments in cognitive science, such as in experiments Gallagher and his colleagues conducted with astronauts (Reinerman-Jones et al. 2013, Bockelman et al. 2013, Gallagher et al. 2014), but Metzinger and Windt also point to the promising use of standardized interview techniques (Metzinger & Windt 2015, 14-15). Nevertheless, cases that incorporate other professions, such as theatre, into cognitive science are still uncommon.

According to Neisser, the reason why we so infrequently participate in such open-minded collaboration is that academics don’t take notice of professional accomplishments outside the university. They are typically more interested in theoretical issues and concepts in social cognition than in the actual social phenomena (Neisser 1980). The aim should therefore be to open up cognitive science in order to further experiment with open-minded collaboration so to become better at using such method for describing and explaining the social phenomena we are interested in.

## 5. Open-Minded Communication

For both OM (Metzinger & Windt 2015, 20) and OS (Nielsen 2012), the internet and online tools are seen as a shared communicative space in which this new open-minded collaboration can take place and flourish. However, when it comes to how they practically use these tools, it is mainly by open access publishing. This is problematic, since open access preserves a conservatism regarding how to do science that contributes to the increasing specialization of knowledge, as Kuhn would state it (Kuhn 2000). Familiarity with specialized terminologies, methods, tools, data and discussions are taken for granted in publications, and scientists have difficulties understanding what is published outside their specific discipline. For the rest of society, it’s almost impossible to understand, which makes open-minded collaboration with others outside one’s own discipline and outside academia extremely difficult. To publish open access doesn’t solve the challenge of communicating science, since the now openly published knowledge is understandable still only for a few.

For Kuhn, limits in communication such as a narrower audience or more technical language are a necessary condition for the specialization of science, but the aim of communicating knowledge should be,

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<sup>8</sup> See chapter 9 in this Ph.D. dissertation.

<sup>9</sup> See chapter 3 in this Ph.D. dissertation.

and has always been, that others can engage with it (see the introductory remarks to the first journal from 1665, *Philosophical Transactions* (Oldenburg 1665)). To communicate means ‘to share’ (from Latin *commūnicāre*), and current discussions in embodied social cognition are all about the meaning of sharing, how reciprocal engagement and we-experience are crucial for communicative acts and how aspects such as bodily language, gestures, mimicking, emotions, haptic engagement, context, etc. are fundamental to such communicative sharing. But where are all these aspects when it comes to the communication of scientific research?

## 5.1. Open Media

Metzinger and Windt stress that the globalization of the world forces us to create novel forms of communication and to experiment with new formats of open access publishing (Metzinger & Windt 2015, 19). What is being argued in this paper is that open access as such is in itself not sufficient. OS scientists typically aim at combining open access with social media, which is the “fluid realm of websites, blogs, file sharing, and social networking: the dynamic, unmediated, uninhibited, and challenging domain of ‘Web 2.0’” (Grand et al. 2012, 683). But no matter how many tweets or blogs a scientist writes, his words don’t have, and will never have, the potential of embracing the embodied experiential and tacit aspects of knowledge. As Dewey phrased it: “There are values and meanings that can be expressed only by immediately visible and audible qualities, and to ask what they mean in the sense of something that can be put into words is to deny their distinctive existence” (Dewey 1934, 80).

A way to rephrase Dewey’s point in another way is to say that ‘a picture says more than a thousand words,’ a position that has been taken literally online. Instagram, Snapchat and other apps have made it possible for people to say much more than a thousand words, and Youtube is one of the most frequently used online tools as well as an audio-visual medium that is used for global communication. One of the reasons why these examples are so commonly used is that they enhance the experience of sharing by means of processes that are able to display embodied and embedded aspects of communication. Meaning is communicated audio-visually through pictures or videos and isn’t specialized for only a few, but is transparent, immediate, universal and ultimately understandable. In comparison to the format of journal publications, such pictures or videos are media for global social sharing, and that’s the reason why people use them.

In order to harness the potential of online communication tools for cognitive science, Martiny and Birkegaard (in progress)<sup>10</sup> sat up an experiment in open-minded collaboration between science and documentary as a way to experiment with new ways of communication. The aim was to go from talking only

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<sup>10</sup> See chapter 10 in this Ph.D. dissertation.



about open access, to in fact talking about open media. Open media is not a question of abandoning the written medium, and, in particular, the format of the journal, but a question of using other media to supplement it. Open media has a lot of potential for science communication as well as for interdisciplinary collaboration, and this has already been seen in a few cases in OS. In the Journal of Visualized Experiments (JOVE), scientists upload videos of how their experiments work so as to communicate tacit knowledge of how to do the experiment and, in the famous example of Foldit, scientists and gamers joined forces in an experimental and collaborative research project on protein folding that used virtual interaction and gamification for doing the science (Copper et al. 2010).

Scientists are not unaccustomed to using other media, since visual tools, such as pictures, graphs and visual imaging, are used to show statistical relation and depict atom models, DNA structures and brain scans. For EC, this should make perfect sense, since the use of visual tools can be described as the scientists' *extending* their cognitive processes (Clark & Chalmers 1998). This can be done in both published journals and PowerPoint and poster presentations, as a way to reduce the complexity of the communicative process.

## 6. The Big Picture: Engaging Science and Society

Open media has certain advantages for science communication, since it uses 'embodied language' that can reach beyond academia. This is necessary so as to illustrate the social dimension of science, a process that, as Metzinger and Windt emphasize, comprises a crucial part of being open-minded. The aim is to never lose sight of the bigger picture, since our research is embedded in a wider context (Metzinger & Windt 2015, 15). They theoretically discuss examples of how open-minded cognitive science will have to take into account ethical, anthropological, sociocultural, global and transcultural issues. These issues are necessary to consider, Metzinger and Windt argue, since new theories in cognitive science lead to new technologies and potentials for action, and change the image of man, both of which may have social and cultural consequences (Metzinger & Windt 2015, 16).

While this is true, Metzinger and Windt overlook one crucial point, which many other OS inspired scientists also overlook when discussing so-called *scientific social responsibility* (Krogsgaard-Larsen et al. 2011): opening up science is a two-way street, and it becomes necessary to highlight the way in which society and science are of mutual relevance and import to one another. As scientists, we shouldn't only be aware of the consequences that our research has for society, but we should also be aware of the consequences that society has on how we should do science.

In this respect, the important question isn't whether or not we publish open access and the taxpayers get their money worth (Metzinger & Windt 2015, 19). The issue is that published knowledge doesn't percolate through society like a one-way stream that flows directly from scientific excellence to societal relevance.

“Academic excellence, however, is often inversely proportional to societal relevance” (Holbrook 2010, 321), a fact that, according to Holbrook, is due to the current validation and evaluation criteria seen primarily in the peer review process. For open-minded cognitive science, academic excellence and societal relevance should go hand in hand, but the challenge one must overcome in order for this to happen is not theoretical. It’s pragmatic.

The relationship between academia and society is essential to cognitive science, since it studies people, who are living their lives in a world outside academia. Current EC discussions in social cognition are focusing on how we should take an interactive turn and adopt a second-person stance for studying people in an engaged way (Satne & Ropestorff 2015). Interpersonal commitment, experiential engagement, and reciprocal and dynamic interaction are seen as crucial to this second-person study but, once again, where are these aspects when the research is being validated and evaluated?

The main issue at stake in these discussions concerns whether or not the interactive turn contributes to the theoretical development of social cognition in opposition to the established mindreading approach. Such theoretical development is essential, but a set of normative guidelines regarding how to conduct, validate and evaluate research should follow when engaging in a second-person study of other persons. The validation and evaluation of this research should not stop at its internal review within the context of researchers’ discussions, but should include the pragmatic and societal relevance it bears for the persons one is studying.

## 6.1 The Use of Pathology

This is especially the case when using pathologies in one’s research, as is extensively done in cognitive science. In Cole’s review of Gallagher and Zahavi’s book *The Phenomenological Mind*, he raises concerns as to how pathology is incorporated into phenomenological analysis in the cognitive sciences (Cole 2008). First all, phenomenologists tend to choose pathologies (e.g. schizophrenia and autism) that already lend themselves to phenomenological analysis and discussion, disregarding other less fashionable pathologies. Secondly, phenomenologists use the cases as part of their arguments, although there’s no clear scientific understanding of the cases. Thirdly, people with pathology typically don’t address topics interesting for phenomenological study, such as pre-reflective self-awareness, but rather talk about issues that are meaningful for them and for their daily life. Fourth, pathologies are typically understood in phenomenology as abnormalities, losses and deficits, but this is a somewhat narrow-minded focus, since part of the wonder is how people adapt and develop according to their pathology. This should also be part of the phenomenological analysis (Cole 2008, 30-32).

Cole criticizes Gallagher and Zahavi for having a top-down view and encourages them to ‘take some walks’ in the places that people actually live. They should get their hands dirty and engage in first-hand

accounts of the experiences of the persons with pathology that they are trying to describe. An attempt to do so have recently been seen in the study of autism, where the aim is to reverse the theoretical glasses and pay attention to what persons with autism can do and how they describe their own experiences (Björne 2007; Robledo et al. 2012; de Jaegher 2013; Donnellan et al. 2013).

In addition, Metzinger and Windt acknowledge that open-minded science is a new way of doing science, one that takes more risks, allows for uncertainty in the research process, endorses falsification as valid knowledge, and sees no research topics as taboo (Metzinger & Windt 2015, 21). The aim shouldn't be strategic with the ultimate goal being to publish in high-ranked journals so as to endorse one's own career and acquire further funding (Metzinger & Windt 2015, 23).

However, being an open-minded scientist, whose research deals with pathology, means more than either getting one's hands dirty or taking a risk and being uncertain in doing so. In studying persons with pathology, we should embody our theoretical considerations by engaging with them, which means that we should commit to and recognize them not solely as organisms, brains, bodies and systems, but as persons (Satne & Roepstorff 2015). They should be included in the research processes in a way that preserves their autonomy and self-control, because now it's not only about driving forth theoretical discussion in cognitive science, but also about doing research for the sake of these people.

## 7. Open Minded Cultivation

Cultivating a new open mindset for doing science is the 'hard problem': changing a mindset into an open one is not something that can be done strategically or by scientific reasoning. It's something that relies on education, know-how, and active collaboration, and it needs new systems of assessment that take openness and collaboration seriously. In relation to education, Hare explains that, if one believes that being open-minded is an important disposition in an educated person, we should expect teachers not only to aim at developing open-mindedness in their students, but to model it in their own practice (Hare 1979, 65).

So, when discussing the above example of how to engage persons with pathology in scientific discourse, what is needed is to do it in one's own practice. To encourage communication between society and the world of science is a key aspect in OS, which stresses that opening up science

“offers the opportunity for public groups to engage not just with the published outcomes of science but also with its processes, including methodologies, codes, models, and raw data. This changes the context: Rather than science being a series of definitive experiments from which emerge polished results, open science supports the understanding of science as a dynamic, tentative, uncertain, and constantly revised activity.” (Grand et al. 2012, 681)

This, however, also changes the way in which we should validate and evaluate the theoretical considerations in cognitive science. It becomes, as mentioned, a question of illustrating the social relevance of academic endeavours. The validation and evaluation should therefore be an open-minded practice, and should consist in the success, efficacy, and functionality of how well the developed pragmatics adapts to both the world of, and the world outside, cognitive science.

It also introduces a different way of understanding validation in science that disposes of the correspondence idea of objective truth (also called the representative idiom) (Pickering 1995, 5). Knowledge is something that we create together and not something ‘to be dug up’. The validation of the theoretical ideas and results presented in EC should therefore be understood in performative and pragmatic terms, highlighting “intersubjective validation” (Varela & Shear 1999, 10), “intersubjective corroboration” (Gallagher & Zahavi 2008, 29-31) and “performative consistency” when doing science (Petitmengin & Bitbol 2009, see also Pickering, 1995). What this type of validation should look like in relation to open-minded cognitive science requires further development, but it should emphasize that validation is an *open-ended* process that is able to include ambiguity, as Metzinger and Windt also point out (Metzinger & Windt 2015, 22). Knowledge processes are as dynamic and uncertain as any other intersubjective engagement.

As it has been argued in open data discussions in OS, in addition to reproducibility, opening up data allows for the evaluation of different hypotheses with the same dataset. The data can be reused and recycled, creating more dynamic conclusions and knowledge (Murray-Rust 2008). As stated earlier, not only should scientists be able to partake in such dynamic evaluation of data, but so should society. This means reinventing the peer review model, so that it’s opened up for others and becomes a more open-ended process, where the ideal aim is to open-mindedly create a dynamic, sharing and collaborative knowledge community in (cognitive) science.

## 8. Conclusion

In this paper I have discussed the notion of ‘open mind’ in relation to the Open MIND (OM) project, recently launched in cognitive science, and the Open Science (OS) movement in general. I have argued that the question of how to be open-minded is not simply one of interdisciplinary collaboration, open access, or the engagement of science with society. Open-mindedness requires a change in mindset regarding how one does science, how one understands open collaboration and open media, and how one understand the way in which society and science are of mutual relevance. For embodied cognition (EC) it requires that we embody our theoretical considerations in our scientific practice, so as to do as we say.

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## Chapter 3

# Framing a Phenomenological Interview: What, Why and How

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# Framing a Phenomenological Interview: What, Why and How

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## Abstract

Research in phenomenology has benefitted from using exceptional cases from pathology and expertise. But exactly *how* are we to generate and apply knowledge from such cases to the phenomenological domain? As researchers of cerebral palsy and musical absorption, we together answer the *how* question by pointing to the resource of the qualitative interview. Using the qualitative interview is a direct response to Varela's call for better pragmatics in the methodology of phenomenology and cognitive science and Gallagher's suggestion for phenomenology to develop its methodology and outsource its tasks. We agree with their proposals, but want to develop them further by discussing and proposing a general framework that can integrate research paradigms of the well-established disciplines of phenomenological philosophy and qualitative science. We give this the working title, a "*phenomenological interview*".

First we describe the *what* of the interview, that is the nature of the interview in which one encounters another subject and generates knowledge of a given experience together with this other subject. In the second part, we qualify *why* it is worthwhile making the time-consuming effort to engage in a phenomenological interview. In the third and fourth parts, we in general terms discuss *how* to conduct the interview and the subsequent phenomenological analysis, by discussing the pragmatics of Vermeresch's and Petitmengin's "Explicitation Interview".

Keywords: Phenomenology, Qualitative Interview, Co-Generated Knowledge, Reciprocal Interaction, Factual (Eidetic) Variation, Explicitation Interview.

## 1. Introduction

Research in phenomenology has benefitted from using exceptional cases from pathology and expertise. But exactly how are we to generate and apply knowledge from such cases to the phenomenological domain? For example, an investigation into the condition of Cerebral Palsy (CP) might expose challenges to our normal assumptions about what it means to have a sense of control over one's body. However, if you want to understand the lived experience of someone with CP, how would you do that? Furthermore, as seen from the McDowell-Dreyfus debate (see Scheer 2013), examples from bodily expertise can be used in parallel with pathology. Such an examination might reveal something fundamental about our ability to reflect and act at the same time. Again, the same question applies: How would you go about examining the experiential life of

for instance an expert musician to characterize the phenomenological structures underlying musical absorption?<sup>11</sup>

As researchers of cerebral palsy and musical absorption, we together answer the *how* question by pointing to the resource of the qualitative interview. We do so because, 1) our cases are exceptional cases of experience to which we do not have first person access and 2) there is little, or no, literature to be found in the phenomenological tradition on these cases of experience. Using the qualitative interview is a direct response to Varela's call for better pragmatics in the methodology of phenomenology and cognitive science (Varela 1996) and Gallagher's suggestion for phenomenology to develop its methodology and outsource its tasks (Gallagher 2012). We agree with their proposals, but want to develop them further. Instead of outsourcing the task, we take full ownership of the entire process by engaging in the interview ourselves.

Many attempts have been made to construct a methodology that combines qualitative research with phenomenology (Georgi, Smith & Osborn or Van Manen). Gallagher (2012, 306) has critiqued these for not being well integrated with phenomenological philosophy. In this paper, however, rather than debating with these approaches, or developing a new method, we discuss how to conceive of a framework that integrates the qualitative interview with phenomenological philosophy. We will simply call this framework a "phenomenological interview". More specifically, we construe this framework in such a way that the interview is informed by certain phenomenological commitments and in turn informs a phenomenological investigation.

We unpack the phenomenological interview in the following way: in the first part we describe the *what* of the interview, that is the nature of the interview in which one encounters another subject and generates knowledge of a given experience together with this other subject. The interview and the phenomenological analysis are framed as a two tier process. In the second part, we qualify *why* it is worthwhile making the time-consuming effort to engage in the phenomenological interview. In the third and fourth parts, we in general terms discuss *how* to conduct the interview and the subsequent phenomenological analysis, by discussing the pragmatics of Vermersch's and Petitmengin's "Explicitation Interview". Here we also provide two cases from our own research in cerebral palsy and expert musicianship to illustrate how our approach differs from that of the explicitation interview.

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<sup>11</sup> The study of musical absorption is related to expertise as it is usually musical experts who most consistently experience such absorption.

## 2. What is a Phenomenological Interview?

To understand what we mean by a phenomenological interview, it is useful to break down the question and first understand the nature of an interview as such. The sociologists Hammersley and Atkinson point to one distinctive feature of the interview in the context of social research:

“It is a distinctive feature of social research that the ‘objects’ studied are in fact ‘subjects’, in the sense that they have consciousness and agency. Moreover, unlike physical objects or animals, they produce accounts of themselves and their worlds.” (Hammersley and Atkinson 2007, 97)

In an interview, one studies another subject, which means that two autonomous subjects, capable of producing accounts of themselves and their worlds, interact together in an ever-developing conversation. In order to generate the knowledge aimed for in the interview, the interviewer should in this study assume a second-person perspective. This means taking up an empathic position whereby that experience and understanding of interviewer and interviewee resonate (Varela and Shear 1999, 10). According to Zahavi, the prime point of a second-person perspective is that of “reciprocity”:

“Perhaps the most unique feature of the second-person perspective isn’t the action part, isn’t the fact that one is aware of others’ mental states as a result of engaging and interacting with them, but is rather the issue of reciprocity (de Bruin et al 2012, Fuchs 2013). On such an account, the second-person perspective involves a reciprocal relation between you and me, where the unique feature of relating to you as you is that you also have a second-person perspective on me, that is, you take me as your you. To that extent, there cannot be a single you: there always has to be at least two. In short, to adopt the second-person perspective is to engage in a subject-subject (you-me) relation where I am aware of the other and, at the same time, implicitly aware of myself in the accusative, as attended to or addressed by the other (Husserl 1973a: 211).” (Zahavi 2015, 12)

In the interview setting, “reciprocity” means that the interviewee is encountered as an autonomous “you” and that the interviewer is also encountered as a “you”, such that these two “you”s develop each other’s understanding and perspectives.<sup>12</sup> Because as an interviewer you enter the interview with specific aims, the encounter comes to be structured in specific ways. You could aim to confirm or reject certain theories about the experience of CP or musical absorption with the help of the interview. You can, however, also engage in a more open interview in which you are not out to confirm already held theories. In either case, you do not come to the interview as neutral. You have some idea about what you want to know, what the interviewee might say, and hence actively participate in the knowledge generation process.

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<sup>12</sup> For a more detailed account of what we mean by encountering, see Legrand 2013a, 33-4; 2013b.

What are the dynamics for co-generated knowledge in the encounter of the interview? Varela and Shear state that the:

“position here is not that of a neutral anthropologist; it is rather one of a coach or a midwife. His/her trade is grounded on a sensitivity to the subtle indices of his interlocutor’s phrasing, bodily language and expressiveness, seeking for indices (more or less explicit) which are inroads into the common experiential ground....Such encounters would not be possible without the mediator being steeped in the domain of experiences under examination, as nothing can replace that first-hand knowledge.” (Varela and Shear 1999, 10)

This necessary first-hand knowledge of the interviewee is first and foremost expressed in the exchange of a lot of discursive knowledge. At the same time, however, a lot of tacit knowledge is generated. Tacit knowledge, in this context, pertains to the way discursive knowledge is communicated. Knowing whether a certain statement is communicated with great conviction or with hesitation naturally changes one’s interpretation of that statement. This kind of knowledge is usually found in one’s body language, facial expression and tone of voice.<sup>13</sup> Further, in the encounter, the knowledge generation process is interactive.<sup>14</sup> Interaction could be understood in a more static manner, by which it would merely refer to a simple kind of communication in which knowledge is exchanged for example in the form of a questionnaire. As already mentioned, however, what we mean by interaction is , a reciprocity that is much more constitutive of the knowledge generation process. The interviewer asks a question and gets an answer that leads him to modify his next question. Thus, both subjects contribute to the knowledge generation process through complex dynamics, which are driven by reciprocal interaction. This kind of interaction strongly affects both the discursive and the tacit knowledge generation process.

Since the encounter does not play out in theoretically neutral space, it is important to be aware of one’s role in the co-generation of knowledge and take responsibility for it by being able to account for one’s theoretical inclination, methodology and pragmatics. In our case, these commitments derive from the philosophical tradition of phenomenology.

## 2.1 Phenomenological Commitments: A Structural Ambition

Although phenomenology is not an entirely homogeneous tradition, in this context of the interview, we take it to conform to some general commitments. The first of these is the classical dictum to go “to the things themselves”, meaning that we take experience seriously, beginning, for example, with the first-person

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<sup>13</sup> The constitutive role of body language, facial expression and emotional expression in consciousness has a long tradition in phenomenology, especially in Scheler. For a more modern treatment see Krueger 2012.

<sup>14</sup> “Interaction” in this context should not be identified with the philosophical position of “interactionism” as coined by De Jaegher and Di Paolo (2007). For a good discussion of interactionism and the notion of “engagement” see Satne & Roepstorff 2015.

perspective of the person with CP or the musician. We try to dispense with pre-established theories, explanations and beliefs about CP or expert musicianship, letting the descriptions themselves come to the fore. However, we are not interested merely in the experiences described by our interviewee:

“Phenomenology has as its goal, not a description of idiosyncratic experience – ‘here and now, this is just what I experience’ – rather, it attempts to capture the invariant structures of experience. In this sense, it is more like science than like psychotherapy. Psychotherapy is focused on the subject as a particular person and may appeal to introspection in its concern about the way and the why of the person’s experience of the world, here and now.... In this sense, phenomenology is not interested in qualia in the sense of purely individual data that are incorrigible, ineffable, and incomparable. Phenomenology is not interested in psychological processes (in contrast to behavioural processes or physical processes). Phenomenology is interested in the very possibility and structure of phenomenality; it seeks to explore its essential structures and conditions of possibility. Phenomenology aims to disclose structures that are intersubjectively accessible, and its analyses are consequently open for corrections and control by any (phenomenologically attuned) subject.” (Gallagher and Zahavi 2008, 28)

Gallagher and Zahavi’s conclusion is important in that it separates the practice of phenomenology from that of introspection (see also Varela 1996, 338-9, Gallagher and Zahavi 2008, 21-3). In accordance with this distinction, we do not believe that the criticism of introspection applies to the phenomenological interview. This is partly so because we are not just interested in the “here and now”. Rather, we intend for our interview to disclose invariant phenomenological structures, such as the sense of control over one’s body in the case of CP or the relation between coping and reflection in the case of expert musicianship. Hence, as our second commitment, we hold that subjectivity has structures that are irreducible and invariant. This also entails that we conceive of subjectivity, the “you” in the interview, as possessing a transcendental and ubiquitous dimension. The “you” can never be reduced to a kind of object, and his experience always transcends the here and now, pointing to “invariant experiential structures that are intersubjectively accessible” (Gallagher and Zahavi 2008, 28).

To understand how these commitments play into the knowledge generation process, we should specify that the phenomenological interview consists of two intricately linked tiers. The first is the interview itself as the second person perspective described above, while the second is a phenomenological analysis of the first tier. In the first tier, we generate descriptions of experiential content and gain intimate first-hand knowledge of the interviewee’s lived experience. In the second tier, relying on the phenomenological method (Gallagher and Zahavi 2008, chap. 2), we analyze these descriptions, in such a way that they might be generalized to say something about experiential structures and hence subjectivity as such.

We need these two tiers because we have direct experiential access neither to the interviewee’s first person-perspective, nor to the invariant structural dimensions of his experience. One might think that the

interviewee possesses the knowledge of the experience we are out to disclose because it is his experience we want to understand. But, since we are after understanding both the first-person experiences and their invariant structures – the latter not voiced in the interview – this is not so. Rather, the interview gives us the possibility to investigate and understand those structures. The function of the second tier is to actualize this possibility.

Although methodologically distinguishable, the two tiers feed into one another and are in epistemic continuity. Tier one feeds tier two by providing the discursive as well as the first-hand embodied and interactive content of the analysis. Inversely, tier two feeds into tier one, especially if one conducts several interviews, by providing the general phenomenological framework for the questions in the encounter. In other words, one's theoretical framework influences the interpretation of the descriptions, but it is also the case that the descriptions sometimes put one's theoretical framework under pressure. The analysis is therefore a dialectical process in which one's view of the meaning of the descriptions changes and in which the analysis develops until one has reached a certain level of consistency whereby one can understand all (or most of) the descriptions in the light of the conceptual framework achieved.

## 2.2. Descriptions and Experience: A Question of Validity

How can we know that this analysis actually is an analysis of the experience of for example CP or musical absorption? First of all, we need to understand the relation between the interviewee's experience and his description of it. We must again remind ourselves that the interview constitutes a second person perspective in which one directly encounters another subjectivity (Varela & Scheer 1999). Understanding subjectivity requires methods fundamentally different from those employed in understanding objects (Varela, 1996; Zahavi 2010). Understanding subjectivity as irreducible to objectivity is our third phenomenological commitment. From a certain scientific perspective, one might think that it is essential to ensure a correspondence between an experience and its description, like an object and the description of the object. One will begin with a doubt, skeptical about whether the description of the experience corresponds to the actual experience. This doubt, however, falls prey to confusion between objectivity and subjectivity. It presupposes that an experience is like any object – an apple, car or planet – but this understanding of experience will lead one to a framework in which the descriptions of experience can be final or complete, where they can be treated as static “data” subject to “reliability” or “reproducibility”.

From a phenomenological perspective, an experience is not a thing one can retroactively return to in a straightforward manner. It has no fixed diachronic stability, hidden inside the head<sup>15</sup> to be dug up by memory, no Archimedean point of reference. It is embodied and enacted in the world together with other

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<sup>15</sup> See Krueger 2014 and Krueger and Overgaard 2012.

experiencing subjects. It is a perspective on the world, marked by ever fleeting contents, but a relatively stable structure. The embodied, enactive and embedded foundation of subjectivity is our fourth phenomenological commitment.

So, in the first tier, we are not testing to what extent the interviewees' descriptions are an accurate representation of their experience as it happened at time T1. Rather, the descriptions are simply a different shape or manifestation of that very same experience. As Zahavi has argued in several places, experience can take different shapes: reflecting and describing should not be seen as a falsification of originary or pre-reflective experience, but should be considered as an opening up of it (Zahavi 1999, 181-9; 2005, 89-96; 2011) The descriptions we generate in the interview, through exploratively interacting to get descriptions that are as rich and nuanced as possible, are simply such a different manifestation of the experience in question. In the encounter, experience becomes an unfolding process that is constituted by loops of memory, reflection, description and questioning in the interview.

The epistemological status of the experience reflected upon and described in the interview is subject to the so-called hermeneutical objection, as acknowledged by Varela and Shear (1999, 13). It is important to admit, as they do, that this objection and problem exist, and that the knowledge we obtain is fallible. But then again, such fallibility applies to all methods that rely on reflection, phenomenology included, as well as to science as such. We believe that our proposal fares no worse than these. As Varela and Shear conclude:

“Indeed no methodological approach to experience is neutral, it inevitably introduces an interpretative framework into its gathering of phenomenal data. To the extent that this is so, the hermeneutical dimension of the process is inescapable: every examination is an interpretation, and all interpretation reveals and hides away at the same time. But it does not follow from this that a disciplined approach to experience creates nothing but artifacts, or a ‘deformed’ version of the way experience ‘really’ is.” (Varela and Shear 1999, 14)

In order to deal with the hermeneutical dimension, we maintain our phenomenological understanding of experience also in the second tier, which means that we do not consider the descriptions as static data, but rather conceive of experience as subject to developing interpretations. Even after finishing the second tier, one can later revisit the descriptions and produce new interpretations, which present the experience in a new or even clearer light. In other words, in the first tier, our desideratum is not some kind of true or accurate representation of experience. Rather, it is simply clear and nuanced descriptions. In the second tier, however, we operate with a different set of epistemological criteria for accessing the validity of the descriptions.

Let us introduce the term “phenomenological consistency”<sup>16</sup> and present two versions to account for our notion of “validity”. Firstly, “internal phenomenological consistency” refers to the ability to make comprehensible all the descriptions found in the interview. The more descriptions that can be made comprehensible under a certain phenomenological interpretation, the deeper the internal phenomenological consistency. “External phenomenological consistency” refers to the ability of the overall account produced to work with and against already established theories of the phenomena in question.<sup>17</sup> External phenomenological consistency is related to the methodological step of “intersubjective validation” (Varela and Shear 1999, 10) or “intersubjective corroboration” (Gallagher & Zahavi 2008, 29-31). The account should be consistent with the relevant theories, but can also be in a position to challenge them. In part 4 we will discuss both internal and external phenomenological consistency in relation to our own research.

### 3. Why Engage in a Phenomenological Interview?

Apart from phenomenological psychiatry, classical phenomenology has not engaged with interviews. Suggesting that phenomenological research could benefit from fundamentally expanding its methods needs a strong qualification. Further, engaging in the interview process and generating knowledge in the above mentioned fashion takes a great deal of time. Not only must it be justified that the phenomenological interview can contribute to phenomenological research, given the time it takes, it must also be shown that it is worthwhile.

To do so, let us introduce the term, “eidetic variation”. Eidetic variation is traditionally understood as a methodological tool in phenomenology: “using our imagination to strip away the unessential properties of things” (Gallagher & Zahavi 2008, 30). It can be understood as a genre of the classical philosophical thought experiment because they both rely on imagination. Zahavi, however, points out that imagination can successfully be supplemented by real-life deviations:

“Real-life deviations can serve the same function as thought experiments. If we are looking for phenomena that can shake our ingrained assumptions and force us to refine, revise, or even abandon our habitual way of thinking, all we have to do is to turn to psychopathology, along with neurology, developmental psychology, and ethnology; all of these disciplines present us with rich sources of challenging material.” (Zahavi 2005, 141-2)

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<sup>16</sup> Petitmengin and Bitbol (2009, 391) write about “performative consistency”. We will return to differences and similarities with Petitmengin’s account later.

<sup>17</sup> In the qualitative literature, these two kinds of consistency are known as “petit” vs. “grand” generalizations (see Ravn and Christensen 2013, 6). Thanks to Susanne Ravn for bringing this point to our attention. We chose, nevertheless, to stay with “phenomenological consistency,” because this term lends itself better to our general methodological discussion.



Gallagher labels the use of “real cases” (2012, 308) or “empirical data” (Froese and Gallagher 2010, 86) for the purpose of a phenomenological variation a “factual variation” (ibid).<sup>18</sup> We endorse this approach, but want to take it one step further.

In interviews, imagination does not stand on its own. It is supplied by the actual variations in the descriptions directly grasped from the interview. That is to say, the invariant aspects are not necessarily directly expressed in the interview as content. Rather, the content, given through the lens of the eidetic variation, points to invariants that are structural. This variation consists in a cross-fertilization of already established phenomenological concepts and invariants found in the content. So, not only can one use an interview for factual variation but, further, one should preferably engage in the process oneself, rather than merely interpreting the results of other researchers. In the following we will refer to an example from the classical phenomenological literature that shows the pitfalls of relying on other researchers’ results. This is an ex negative argument for engaging in the interview oneself.

### 3.1 “The Schneider Problem”

An example of not engaging in the encounter for the purpose of factual variation is pointed out by Rasmus Jensen (2009). It concerns Merleau-Ponty’s reading of the researchers Gelb and Goldstein’s famous case of the 24 year-old mineworker Johann Schneider, who was wounded by grenade-splinters in the back of his head during World War I. In one instance, Merleau-Ponty uses a quotation from Goldstein thinking that it describes Schneider’s pathology. However, the first-person description in question doesn’t come from Schneider, but is Goldstein’s own description and interpretation of how normal people experience the routine actions of everyday life. Goldstein is trying to argue that when it comes to the movements of our everyday life there is no distinguishable difference between Schneider and a normal person (Goldstein 1923, 175. See Jensen 2009, 382). In other words, Merleau-Ponty takes Goldstein’s first-person description of normality as Schneider’s first-person description of pathology. This leads to an inconsistency in Merleau-Ponty’s understanding of the Schneider case, as several scholars have emphasized (Dreyfus 2007c, 63-4, 69; Jensen 2009, 385-97).

In this respect, neuroscientist J. Cole has criticized the use of pathological cases among phenomenologists, since they use the cases as part of their arguments, even though there is no clear scientific understanding of the cases. He calls it the ‘Schneider’ problem, since the “case of Schneider...is quoted widely by phenomenologists, and yet I, for one, am not clear quite what psychiatric problem he had” (Cole 2008, 26). This being said, we believe that Merleau-Ponty would have gained a deeper understanding of Schneider, and probably avoided the misunderstanding of Goldstein’s descriptions, if he had directly

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<sup>18</sup> This conception of a factual variation has an epistemic status similar to Flyvbjerg’s “case study” (2011). Briefly put, this concerns the power of the case study to add to or find flaws within an established theory.

interviewed and engaged with Schneider himself.<sup>19</sup> This point is also raised by Sheets-Johnstone who questions if empirical data shouldn't always be followed up by personal observations. Shouldn't Merleau-Ponty have interviewed Schneider at the clinic where he was treated, observed other patients at the clinic and talked to Gelb and Goldstein in person (Sheets-Johnstone 1999, 277)?

It is precisely at this point that the phenomenological interview is called for. When using other researchers' empirical data, Merleau-Ponty, as well as Zahavi and Gallagher, are forced to treat it in the third person. This third person data is then used philosophically for the factual variation. In other words, there is an epistemological discontinuity between others' data and one's own interpretation. In contrast, in the phenomenological interview process, the tier one first-hand encounter and the tier two phenomenological analysis are in constant interchange, in epistemological continuity. If an ambiguity arises at the level of description, rather than approaching it as fixed or unalterable data, and beginning one's process of interpretation, one can return to the interviewee and ask for clarification. Our knowledge remains open to being revisited and re-interpreted. Ultimately, one can never avoid making interpretations, but one's aim in the interview is to get descriptions that are as clear, detailed and unambiguous as possible.

### 3.2 Taking Enaction, Embodiment and Embeddedness Seriously

We have argued that the interview yields a unique source of knowledge. As mentioned, the knowledge attained through the interview is co-generated. We would now like to elaborate on this idea by establishing that the knowledge generated is unique also because it is enacted, embodied and embedded. Phenomenological orthodoxy takes one's embodiment as well as one's embeddedness to play a constitutive role in experience (Varela et al. 1991, Gallagher 2005, Gallagher and Zahavi 2008, Thompson 2010). Now, if one believes that experience is constituted at least in part by one's agency, body and socio-environmental context, it seems to follow that, if one wishes to understand a given experience as thoroughly as possible, then one ought to include a consideration of enaction, embodiment and embeddedness in one's general method. This methodological claim was part of Varela's original contribution in introducing the method of neurophenomenology and in arguing for an enacted, embodied and embedded cognitive science (Varela 1996, 346). Compared to the decontextualized and disembodied knowledge gained in reading data or transcriptions about someone else's experience, the encounter directly confronts us with these aspects of experience. The reciprocal interaction and the embodied and contextualized nature of the encounter directly feed into the generation of knowledge. As already described, we gain access to the interviewee's experience by assuming an empathetic second-person perspective and by coming to know in a first-hand manner the accompanying gestures of a certain description, as well as the way and context in which it took place.

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<sup>19</sup> Tatossian makes the same objection to Merleau-Ponty's methodology and argues that we should "engage directly with the madman" (Tatossian 2002, 12). See also Zahavi 2010.

Through the encounter, our factual variation has an advantageous epistemological foundation over that which simply relies on data produced by other researchers. We are thus in line with Gallagher when he argues that it is not enough for phenomenology to accommodate empirical data: “it must also attempt to come to terms with appropriate scientific research methods” (Froese and Gallagher 2010, 86). We believe that the phenomenological interview can be one such research method, which also answers to his critique of the promise to use phenomenology as a basis for qualitative research (Gallagher 2012, 306).

### 3.3 Practical Applications

In this article, we present the phenomenological interview as a general framework. In doing so, we hope to engage, on the one hand, researchers outside of, but with an interest in, the discipline of phenomenology and, on the other hand, phenomenologists interested in expanding their methodological framework. This aim, as demonstrated above, would not only benefit the theoretical work done within phenomenology and fields engaging with phenomenology, but we also believe it would benefit the practical applications of phenomenology. Many fields outside phenomenology use phenomenological methods, concepts and theories for practical purposes, such as in the practice of expertise, athletics and meditation, in the development of clinical practices or in the education of for example nurses, doctors, psychologists and architects. However, reiterating Gallagher, we have claimed that these practices are not well integrated with phenomenology. Therefore, the third answer to the *why* question is that not only philosophers, but also people from all the above-mentioned fields, would hopefully be able to improve their practices with some of the thinking we put forth.

In this context, the qualitative interview is of great use, since many of the abovementioned groups already have extensive knowledge of the methodological and practical aspects of interviews. A task of this paper has been to set up a general framework in which practitioners with a phenomenological interest can work with a phenomenological perspective. We are not going to present an overall manual for how to do so, since, depending on one’s field and practice, one’s intended output, and the person one is interviewing, it should be adjusted to serve specific purposes.

There are already good examples of how to combine the resources of both phenomenology and the qualitative interview. For example, in the clinical work on schizophrenia, the EASE (Examination of Anomalous Self-Experience) framework shows how, through the use of interviews, the field of psychopathology and psychiatry benefits from phenomenology and vice versa (Parnas et al. 2005). The work done by Ravn and Legrand on the expertise of dancers also shows how both ethnographical research and phenomenology can be combined through the use of qualitative interviews (Legrand and Ravn 2009. See also Ravn forthcoming). The most well-known example is the use of interviews within the so-called method of neurophenomenology to help combine neuroscience and phenomenology (Varela 1996, Lutz et al. 2002,

Lutz 2002, Lutz and Thompson 2003, Reinerman-Jones et al 2013, Bockelman et al. 2013, Gallagher et al. 2014, Colombetti 2014, chap 6.). This combination can have therapeutic effects as seen especially in the work of Petitmengin on epileptic seizures (Le Van Quyen and Petitmengin 2002, Petitmengin et al. 2007). In neurophenomenology, a specific kind of interview is typically used, namely the Explicitation Interview (EI) as developed by Vermersch and Petitmengin.<sup>20</sup> We will in the two final parts of the paper discuss EI in order to draw out the pragmatics of our general framework of a phenomenological interview.

## 4. How to Conduct a Phenomenological Interview: Tier One

Phenomenology has been criticized on various fronts for not having developed appropriate methods that incorporate pragmatics from the second-person perspective. Varela's development of neurophenomenology (1996) and Vermersch's development of the "Explicitation Interview" (EI) (1994) are both responses to such a critique. Vermersch develops his interview method while attempting to reinterpret and improve the use of introspection (Vermersch 1999). This might at first seem to be in contrast to the phenomenological tradition, which historically has criticized introspective psychology and sought to develop a more rigorous method for describing experience. Vermersch, however, turned to the tradition of introspection, because it has a more developed pragmatic approach than classical phenomenology, which has not concerned itself much with practice (Ibid, 17).

In this paper, as mentioned, we cannot and do not wish to provide a manual for a phenomenological interview. However, we certainly take Varela and Vermersch's above criticism very seriously and therefore wish to address exactly how the pragmatics of the interview functions in our general phenomenological framework. To this end, in the following, we present two sections that further develop the two tiers of our framework.

In relation to the first tier, it is crucial to stress that one primarily learns to conduct an interview by doing it. In other words, as interviewing is an embodied skill to be acquired, one cannot provide an exhaustive manual of its pragmatics. Nevertheless, one can of course learn a lot of specific interview skills by reading up on qualitative science methodology, which provides good rules of thumb and lots of examples of best practice (e.g. Brinkmann and Kvale 2014, Allen-Collinson 2009, Flyvbjerg 2011). However, as mentioned, the focus of the phenomenological interview is not only to understand the experience of the interviewee, but more importantly to understand the invariant phenomenological structures of this experience. In this respect, and as phenomenologists, our questions have a different orientation from those of qualitative researchers, anthropologists, ethnographers, sociologists and psychologists.

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<sup>20</sup> In this paper, we use the claims of Vermersch and Petitmengin interchangeably.

The method that comes closest to the phenomenological interview is EI. Over the following pages, we will introduce and discuss the pragmatics of EI and provide examples from our own research into CP and musical absorption. We do so because what we share with EI, we believe to be of the essence of the pragmatics at play in a general framework of a phenomenological interview. Despite a shared essence, however, due to some theoretical differences, as will become apparent, we put a different weight on the second tier of phenomenological analysis. Further, EI has more elaborate pragmatics for developing descriptions in the first tier. What we will bring out in the following is how different theoretical commitments give rise to differing pragmatics.

## 4.1 The Explicitation Interview

We have earlier presented the general hermeneutical difficulty pertaining to the relations between experience, reflection and expression. In addition to this come more specific difficulties such as giving descriptions that are adequately detailed rather than general, stabilizing one's attention to one's experience and then rendering that experience into words. Petitmengin (2006) has done excellent work in systematically presenting these difficulties in her EI framework. In this paper we cannot do justice to all the details of EI, and in the following present a mere overview. Further, taking our own commitment to epistemological continuity between the generation of data and its subsequent interpretation seriously, we here run the risk of misrepresenting EI as we haven't been trained in the method.<sup>21</sup>

In a recent overview, Bitbol and Petitmengin take the interview process of EI to consist in leading the interviewee "to realize the following acts" (2013a, 273): Moving from descriptions or explanations of experience in general to descriptions of particular, singular lived experience. This is equivalent to moving the focus of attention from a belief about past experience to actual descriptions of it. This is done by repeatedly reenacting and thereby *evoking* (Vermersch 2012, 2) selected time slices of the targeted singular experience situated in time and space. Such attention has to be stabilized by inviting the interviewee to suspend any other concern, by reformulating the last pieces of the report given in order to constantly question the interviewee, and finally by bringing the interviewee back to the thread of descriptions if she starts judging or explaining it. The interviewer constantly leads the interviewee to turn her attention from the "why" and "what" of experience to the important "how" of its givenness: "In other words, moving attention from the narrow *content* to the complete *act* of consciousness, which is tantamount to performing the phenomenological reduction" (Bitbol and Petitmengin 2013a, 273). We here start to notice the attempted *rapprochement* of the theories of introspection and phenomenology. Let us put that aside for the moment and describe in more detail the specific questioning technique.

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<sup>21</sup> We have met with Petitmengin and experienced a brief tutorial. Our understanding of EI is thus formed from this encounter as well as from all the publications on EI.

EI takes inspiration from so-called “Ericksonian language”<sup>22</sup>, which, among other things, emphasizes the use of a specific kind of open question in contrast to closed questions (Vermersch 1999, 36; Petitmengin 1999, 47; 2006, 250-2). By their formulation, open questions do not already presuppose more knowledge than they aim to gather, whereas closed questions introduce biases in their formulation and already suggest possible answers to the questions, as well as concepts useful for verbalizing them. An example of a closed question could be: “when you played the concert yesterday, were you in a state of deep absorption or not?” Open questions, in the EI context, should be “directive” and guide the interviewee to focus on the concrete and singular experiences that the interviewer is interested in understanding (Petitmengin 2006, 252). This is done by reformulating the last piece of the report into a question and inviting the interviewee to check and further develop the accuracy of the reformulation.

Petitmengin presents the following example of using open “how” questions to guide the interviewee to describe an experience of concentrating:

- “I am concentrating
  - What do you do to concentrate?
  - (...) I am listening to what is happening inside me.
  - What do you do to listen? If you wanted to teach me how to do it, what would you tell me?
  - (...) First, I am going to put my consciousness much further towards the back of the skull.
  - What do you do to put your consciousness at the back of the skull? (...)
- And when to the questions: “What do you do to ...”, “*How* do you know that ...”, the interviewee begins to answer: “I do nothing”, or “I don’t know”, the interviewer, in order to encourage the emergence into consciousness of the pre-reflective dimension, may use ‘Ericksonian’ language:
- And when you do nothing, what do you do?  
 And when you don’t know, what do you know?  
*How do you know that you don’t know?”* (Petitmengin 2006, 250. Our italics)

We here see the Ericksonian language at play. The kind of questioning above employs an guided kind of bracketing, which is intended to: “encourage the emergence into consciousness of the pre-reflective dimension”. The purpose of such guided bracketing is, according to Vermersch and Petitmengin, to avoid getting caught up in a so-called natural, naïve and basic attitude, which would aim at understanding only the content of the conscious experiences (Petitmengin and Bitbol 2009, 384-7). This shows that EI is influenced by phenomenological methodology and that their main interest in the interview is addressing the pre-reflective dimension of experience (Vermersch 2009, 40 and Petitmengin 2006, 231).

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<sup>22</sup> Milton Erickson was an American psychotherapist specializing in hypnosis. Ericksonian language is language that is empty of content, namely language that refers to the subject’s experiences without introducing and naming the content of the experience beforehand (see Petitmengin 1999, 47).

## 4.2 Getting to the Pre-Reflective

To Petitmengin, the pre-reflective is that which is “not yet conscious” (Petitmengin 2007, 55, Note 1). A strong interpretation of this statement is that pre-reflective experience is not conscious at all, but this would be a misunderstanding of the notion ‘pre-reflective’ (Zahavi 2011a, 9-10). Instead, it should be understood as that which is not yet reflectively conscious. Prior to the interview, it was not available to reflection and verbalization, but EI provides this access. Vermersch elaborates that there are different descriptive ‘layers’ of all lived experiences and that descriptions can be carried out with different degrees of ‘granularity’ (Vermersch 2009, 51). The aim of EI is to arrive at the degree of granularity where the targeted pre-reflective ‘layer’ of lived experience becomes discursively apparent. Petitmengin sees this as a ‘deepening’ of the descriptions to the required level of precision (2006, 248). The interviewer already has a meta-knowledge of the preferred level of deepening and uses open questions to “help the interviewee to stabilise his attention on this unusual level of detail, in order to become aware of pre-reflective internal operations, particularly tests, comparisons and diagnoses that are highly implicit” (Petitmengin 2006, 249, *our italics*). Getting to this level of pre-reflective knowledge is what Petitmengin calls the “reduction” (Petitmengin and Bitbol 2009, 385-6).<sup>23</sup> However, we should distinguish the devices that make it possible to elicit the reduction in an interview context and the reduction itself (*ibid.*, 385). Petitmengin and Bitbol mention the devices that we have already described, namely bracketing and the use of open questions, and end up arguing that if we use these devices of reduction the interviewee will ‘come into contact with’, or in other words ‘get closer and closer to’, the pre-reflective experiences (Petitmengin and Bitbol 2009, 386-7).

When the interviewee is giving her descriptions, she should also be in a ‘speech position’ or ‘embodied utterance position’, which is indicative of whether she actually ‘comes into contact’ with the pre-reflective experience (Petitmengin 2006, 256-7; Bitbol & Petitmengin 2013a, 273). Petitmengin argues that there are objective indicators that can be used in order to identify whether the interviewee actually is in a preferred speech position. These indicators can for example be the vocabulary used to give the descriptions, the direction of the eyes when giving the descriptions, the flow of the descriptions and the bodily gestures. Thus, the EI interview method has an elaborately constructed process and specific practical devices to ensure that the interviewee directly verbalizes his pre-reflective experience.

Petitmengin and Vermersch were not finding adequate pragmatic support in classical phenomenology for using interviews in order to understand others’ experience. Therefore, they turned to the tradition of introspection, mixed with therapeutic (Ericksonian) and Buddhist inspiration (Petitmengin 2006, 232), and

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<sup>23</sup> This reduction is supposed to refer to the classical phenomenological reduction. We would like to see this claim elaborated, as the phenomenological reduction can be several things and is furthermore easily confused with the *epoche*, namely the bracketing of pre-suppositions that they also use (Petitmengin and Bitbol 2009, 384-5). See Luft 2012 for a clarification of this aspect of Husserlian methodology.



attempted to introduce phenomenological theory into the pragmatic context of introspection.<sup>24</sup> We suspect that the attempted integration of at least three different theoretical frameworks (phenomenology, introspection, and Buddhist philosophy) leads to confusion. Vermersch states that, “as far as the actual practice of gathering information about one’s own experience is concerned, there are no major differences in acts between phenomenological ‘reflection’ and psycho-phenomenological introspection” (Vermersch 2009, 25). This statement is based on his view that if one suspends the transcendental aim of phenomenology then the pragmatics of phenomenology and introspection are similar, albeit carried out under different specific presuppositions. Petitmengin and Bitbol don’t seem to share this view, since they either distance themselves from using the term ‘introspection’ (Petitmengin and Bitbol 2009, 379) or redefine introspection as “expanded mindfulness” (Bitbol and Petitmengin 2013b, 183). It is difficult to see how phenomenological reflection, introspection, and expanded mindfulness can all refer to the same thing and even be combined in the same interview methodology. The term “introspection”, in particular, seems problematic.

In this respect, Zahavi writes that there are some fundamental phenomenological problems in talking about pre-reflective experiences as ‘internal’, something that you can ‘come into contact with’ or ‘get closer to’ (Zahavi 2011a, 13). As we have mentioned earlier on, an experience is not something purely internal to be dug out. Further, it does not have the kind of object-like properties that allows one to get “closer to it” or “come into contact with it”. Zahavi suggests that it would be wiser for Petitmengin and Bitbol to stick with the terminology of noticed/unnoticed, i.e. that pre-reflective experiences are something experientially unnoticed. In their reply to Zahavi, Petitmengin and Bitbol acknowledge his point (2011, 24), and say that the pre-reflective is what becomes accessible in the interview, explained by means of the feeling the interviewee has when realizing the richness of the experiences he lived through. In more recent work, they write that critiques like Zahavi’s “target an abstract image of introspection rather than introspection *per se*” and that they want to “quickly overcome them and see if a concrete project of rebirth of introspection can meet them *in practice*” (Bitbol and Petitmengin 2013b, 175). This rebirth consists in understanding introspection as an “‘enlargement of the field of attention and contact with re-enacted experience,’ rather than ‘looking within’” (Bitbol and Petitmengin 2013a, 269). This seems to be a reformulation of introspection that to some extent meets Zahavi’s worries. Nevertheless, one central issue remains, namely that experience is conceptualized such that one can “re-enact” it. In the context of the interview, to ensure this re-enactment, EI needs to operate with the pragmatic elements of bracketing, reduction and objective indicators to “enlarge the field of attention and contact with re-enacted experience” that gets us to the pre-reflective structure of experience. Petitmengin and Bitbol write that the open “‘content empty’ questions help

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<sup>24</sup> On par with other recent approaches, EI seems to be a melting pot of introspection, phenomenology, Buddhist philosophy and meditative techniques, and in some contexts even therapy, education and knowledge management (Depraz et al. 2003. See also Varela et al. 1991; Varela and Shear 1999; Thompson 2014; Colombetti 2014).



the subject to become aware of the different structural — diachronic and synchronic — dimensions of his experience, and to give a verbal description of them” (2011, 385).

By contrast, we believe that our positive proposal evades much of the confusion described above. We do not subscribe to the idea that, with the correct methodological steps, experience can be re-enacted in the interview. Rather, as mentioned, in a phenomenological interview the experience is co-generated by interviewee and interviewer together. We hold this to be the primary access to experience in the interview and cannot subscribe to the idea that one can re-enact it. Therefore, the object of analysis in our case is the co-generated description of experience, and it does not make sense for us to operate with a series of strict steps to ensure its re-enactment and thus access its pre-reflective dimension. In the first tier, we ‘only’ try together to get descriptions that are as detailed and nuanced as possible. In some cases, the interviewees do notice aspects of their experiences they hadn’t noticed before, but this doesn’t mean that they are re-enacting the lived experiences we aim to understand.

On our proposal, we then see the weight shift slightly away from the first tier to interpretive analysis in the second tier. The structural aspect of experience is something that we arrive at through phenomenological analysis of the co-generated descriptions. Before going into the details of the second tier, we will now give examples of the first tier of the interview processes from CP and musical absorption.

### 4.3 Cerebral Palsy

‘Cerebral Palsy’ (CP) is typically defined as a group of disorders in the development of postural and motor control, occurring as a result of a non-progressive lesion of the developing central nervous system (Bax et al. 2005). In 90 % of the cases, the lesion, especially in the upper motor neurons, occurs during pregnancy, and CP is the most common type of congenital disorder associated with lifelong motor impairment. The overall aim of the interview was to understand the bodily experience that persons with CP have when performing their everyday actions. The interviews focused on the most common type of CP, spastic CP, and attempted to represent the diversity of spastic CP by including 14 participants: 7 women and 7 men, all Danish citizens, from the age of 23 to 57 years old, with a diverse range in the nature and degree of severity of bodily impairment.

The interviews was semi-structured, focusing on the experiences that persons with CP have of their own bodies, and were intended to address the structures that inform one’s sense of control. The questions were in the first few pilot interviews inspired by the dominating phenomenological (hermeneutical) approach to disorder, and addressed the supposed objectification, alienation and disruption of their embodiment (Zaner 1981, Leder 1990, Toombs 1992, Svaneau 1999, Carel 2008, 2013). However, from the very beginning of the interviews, when asked very broad questions like “Can you describe how you experience living with CP in your daily life?” or “How does CP express itself in your daily life?” all of the interviewees emphasized the

problems of actually describing living with CP, since it is congenital. They were born like this and have never tried or experienced anything different. There has never been a 'before' or an 'after', which would make it easier for them to describe their experiential differences. This meant that, first of all, expressions of objectification, alienation and disruption only came up in very few descriptions and that, secondly, it was difficult to conduct the interviews, proceed to more concrete questions, and achieve detailed, clear and useful descriptions of the interviewees bodily experiences, all of which should serve as the basis for the second tier. Many descriptions that they gave about their bodily experiences in the beginning of the interview were therefore brief and conclusive: 'That's just the way it is', 'I never notice it', or 'That's just me.' Furthermore, since the interviewees have been part of the Danish healthcare system their entire life, meeting with healthcare professionals on a weekly basis, they give in many instances medical, neuro-physiological and therapeutic explanations of their experiences, instead of their own descriptions: "My doctor says that the reason why I experience..." or 'According to my physiotherapist these experiences arise because...'

However, during the interviews and due to persisting and repetitive questioning, the descriptions became more concrete, addressing specific situations where the bodily experiences of living with CP came to the forefront, such as 'riding a bike', 'walking down a staircase', 'tying one's shoes', and 'participating in sports or other social activities with peers, family, friends and colleagues'. When addressing these concrete situations and experiences by asking open 'how' questions like 'How do you experience your body when walking down a staircase?' or 'How would you describe the experience of riding a bike?' the answers provided very detailed descriptions, as seen in the description given by *FN*, a 39-year-old spastic tetraplegic:

"So if you are trying to get your legs moving when riding a bike there is always the experience of resistance in doing the movement, and although I think: 'come on, increase the pace', because I feel I can do it in my body and my head, it's not what my legs are doing. They have their own pace, and sometimes I experience that if I try to force them, then the stiffness, the spasticity, works against me...In the end I'm totally stiff and I stop completely."

This description was then followed up by more open 'how' questions, e.g. 'how do you experience being totally stiff?' Of special interest, was the interviewees' use of analogies between their own experiences and what they imagine or think must be 'normal' experiences of the situation. For example, in order to express their experience of riding a bike or walking down a staircase, they give descriptions like: 'I imagine that my experience of my body while riding a bike is like always having weights around your ankles' or 'The experience is like if you had to walk with weights on your feet, but I have just never had the weights off my feet.'

In the end, all the interviewees gave very detailed descriptions of concrete experiences and situations in their daily life. Common to these descriptions were the expressions of actually having a ‘certainty’ in and ‘control’ of their bodily movements, despite their spasticity. These descriptions, as well as the expressions and concepts used in them, became the main focus of tier two.

#### 4.4 Musical Absorption

Høffding’s work aims at understanding the phenomenological character of musical absorption. Many musicians claim to occasionally experience a trancelike state of absorption while playing, an apparent selfless state seemingly marked by a complete lack of awareness. To investigate this and to understand the nature of musical absorption in general, Høffding engaged in a series of interviews with, and observations of, the world-renowned classical string quartet, “The Danish String Quartet”.

In the first tier, Høffding prepared a number of questions to guide a semi-structured interview. He was working under a number of assumptions, a central one being that “selfless” absorption or “mindless coping” (Dreyfus 2006, 2007a, 2007b, 2013) is an example of consciousness without a “minimal self” (Zahavi 2005, 2011b), or that there can be awareness without self-awareness, thus opposing a central tenet in the phenomenology of Husserl, Sartre, Henry, and Zahavi. The interviews were intended to enable Høffding to draw conclusions about the nature of self-awareness, and the invariant structures of musical absorption.

In the interview situation, it did not make sense to ask “do you experience losing yourself, while playing?” or “Do you often experience black-outs while performing”. These would be closed questions, eliciting a yes or a no. Rather, Høffding was looking for descriptions of concrete experiences: “When on your own, how do you practice; is there anything in particular you focus on?” Because of Høffding’s background and theoretical preferences, it was easy to evaluate what kinds of answers were interesting and which were not. In other words, alongside the interview, there was an ongoing implicit philosophical analysis of what answers could be used for phenomenological insights, how they could be categorized, how they spoke to one’s preconceptions and whether they contradicted one another. For those that seemed to be the most interesting, Høffding asked for elaborations and, in cases where they contradicted something mentioned earlier, he sometimes intervened more forcefully, as the explicit presentation of the interviewee’s statements as contradictory was likely to spur further reflection and description.

The DSQ members did not need much time before they began talking about their experiences of absorption, probably because such experiences are generally considered artistically significant, but certainly because they are existentially significant, imprinted with intensity in their memory.<sup>25</sup> Nevertheless, most of

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<sup>25</sup> Deep absorption is interestingly paradoxical when it comes to memory. On the one hand, musicians cannot remember what was going on during a deeply absorbed performance but, on the other hand, they clearly remember that they had an unusual experience and can often tell the exact time and place of its occurrence.

the descriptions were brief, à la “black-out”, “meditation-like” or “in a trance”, and the musicians were acutely aware of their inability not just to give expression to the experience, but to retroactively access the experience. About one year subsequent to the first set of interviews, going back to the first tier in a new set of interviews, Høffding and the quartet members were able to generate longer, more precise, but also more poetic descriptions that pointed to a change in the sense of agency during the experience of deep absorption.

One of the most exciting aspects of the interview was its unpredictability. Often the most interesting descriptions emerged from a scattered comment or anecdote, perhaps even after the interview was formally concluded. One could not in advance know what questions would be the most successful. A simple and seemingly straightforward question to the cellist, “How do you actually play a phrase?” happened to be the most complex for him. It animated a description equivalent to four transcribed pages of the minutest of details on how one progresses from one note to the next, on musical authenticity and on the nature of concentration, material that altogether is of immediate value to phenomenological development.

## **5. How to Conduct a Phenomenological Interview: Tier Two**

Having gone over the pragmatics of tier one in the two case studies, it is now time to look at the second tier, which has to do with the analysis of the experience as encountered in tier one and how to account for its validity.

### **5.1 Performative Consistency and Validity in Action in EI**

If experience is something one can get “closer and closer” to, then one is forced to determine criteria for whether one has achieved adequate closeness. These criteria are not to be understood in “traditional introspective studies” as pertaining to a “correspondence theory of truth” between experience and its description (Bitbol and Petitmengin 2013a, 270). Bitbol and Petitmengin stress that in EI, as in any scientific method, there should be what they call ‘performative consistency’, which “consists of an agreement among a) the theories, b) the construction of devices and the understanding of their functioning, c) the theoretical guidance of measurements, and d) the results (Pickering, 1995)” (Petitmengin and Bitbol 2009, 391). They give examples of astronomy and neuroscience and argue that, even in these sciences, researchers only have access to and engage with the ‘data’ through instruments and recordings, meaning that they don’t have access to the actual astronomical events or the activity of the brain as such. It is tempting to think that, when scientists give convincing explanations, those explanations are validated through a correspondence between the theory and its external object. However, what is in fact the case, they argue, is that the explanation is validated through performative consistency. This consistency should also hold in research into experience, which means that validity “is no longer measured in terms of ‘truth’, of representative exactitude, or

adequacy in relation to a pre-existing experience, but according to the manner of its genesis, the quality of contact with the experience in which the description originates, and the remoteness of its source” (Petitmengin 2006, 257-8). In other words, the validity does not in the first place concern the descriptions, but the acts of re-enacting, turning attention, stabilizing attention, etc. performed by the interviewee. Petitmengin and Bitbol call this ‘validity in action’ (2009, 400).

They justify this new concept of validity by referring to the kingpin of any scientific validation, namely reproducibility: a result must be reproducible, at least potentially, by any researcher. Here, validity should be understood in relation to the interview process, which means getting the interviewee to perform the acts that ensure validity in action. The aim is to set up an exhaustive prescriptive method for how to ‘correctly’ conduct an interview, such that other interviewers can be trained in the process that leads the interviewee to perform the acts in question. Via Ericsonian language, objective indicators and validity in action, EI has achieved a prescriptive manual-like procedure for the interview, a procedure that can be taught to others.

We acknowledge the overall idea of consistency between one’s theories, interview process, descriptions and analysis, and that other researchers should be able to be trained in working with a phenomenological interview. Nevertheless, we do not operate with a manual-like procedure for performing the interview and do not strive to reproduce the aforementioned acts that indicate a re-enacted or evoked experience because we don’t subscribe to the idea of re-enactment in the first place. Instead, we emphasize that in the interview process one should be aware of one’s phenomenological commitments, take up an empathetic, reciprocal and second-person perspective when encountering the subject, and ask specific open questions in order to get descriptions that are as detailed as possible. In this respect, one has to remember that interviewing is an embodied skill to be acquired. One cannot provide an exhaustive manual of its pragmatics.

Having no manual-like procedures, but only recourse to detailed and clear description, how do we define the point at which the descriptions are sufficiently clear to enlighten a phenomenological analysis? How do we ensure validity in our work?

Our answer is that there is no point at which the descriptions are sufficiently clear to enlighten a phenomenological analysis. In our framework, there is no such thing as a wrong or incorrect description and, therefore, it makes no sense to ensure the truth or reproducibility of a description in the interview. However, it is of course important to maintain the distinction between clear and less clear descriptions. We can take this stance is because we have a second tier where the validity of the interpretations of the descriptions comes into question. In this second tier, we rely on the traditional analytical work of phenomenology and use the descriptions from the interview as a point of departure for phenomenological analysis. We will now exemplify how we analyze the material from tier one through a phenomenological lens and how we conceive of phenomenological consistency as a development of EI’s performative consistency.

## 5.2 Cerebral Palsy

The main work of the second tier was the transcription of the interviews, the thematization of specific descriptions of, in this case, the bodily experiences of CP, and the phenomenological analysis of these experiences (see Martiny 2015; under review)<sup>26</sup>. The transcriptions were done by additionally focusing on the video recordings of the interviews, since several of the interviewees were difficult to understand solely based on the tape recordings, due to speech impairment. After transcribing the interviews, Martiny made use of the phenomenological method of bracketing, so as to bracket the many medical, neuro-physiological and therapeutic explanations the interviewees gave of their experiences. This wasn't done to exclude these explanations from the analysis, but to focus, as a point of departure, on the interviewees' descriptions of their bodily experiences when performing daily actions. These descriptions were structured into several experiential themes where the experience of 'bodily certainty' and of 'bodily control' became the primary focus of the analysis.

In the analysis process, Martiny used the many different descriptions of these specific experiences as a means of factual variation, which helped to point to invariant structures of the experience. These structures concern the so-called *sense of control* that is an experiential aspect of human agency, and the interpretation of the descriptions illustrated how a sense of bodily certainty and control relates to our agency. Understanding this structural dimension of the experiential life of CP meant making the descriptions that relate to the experience of bodily certainty and control comprehensible in themes, and granting the analysis of these themes an internal phenomenological consistency.

Part of the analysis process consisted in relating the descriptions and interpretations of the interviewees' experience to phenomenological work already done on pathological distortion of one's sense of agency, bodily certainty and control in, for example, cases of schizophrenia, serious illness, OCD, depression and anxiety disorder (e.g. Fuchs 2010, Meynen 2011a and 2011b, Carel 2013, de Haan et al. 2013 and forthcoming). Martiny presented drafts of his analysis at phenomenological and cognitive science conferences as a way to engage the phenomenological community with the descriptions and interpretations garnered from his interviews with persons with CP. However, most of the time was spent discussing his analysis with neuro-physiological researchers and healthcare personnel (physiotherapists, occupational therapists and psychologists) working daily with CP. These presentations and discussions led to several reinterpretations of the above descriptions and to the writing of new drafts. They also led to the inclusion and discussion of empirical data from other studies of CP in the interpretation of these descriptions. All these attempts to communicate and discuss the analysis of the interviewees' descriptions within both

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<sup>26</sup> See chapter 4 and 6 in this Ph.D. dissertation.

phenomenology and other relevant fields are an example of creating external phenomenological consistency in their interpretation.

One of the overall conclusions of the analysis, as presented in Martiny (2015)<sup>27</sup>, was that this case study challenges the few phenomenologically inspired studies focused on CP (Sandström 2007, Peckitt et al. 2013), as well as the dominating theoretical framework of phenomenological research regarding one's sense of agency, bodily certainty and control. It's typically not the case that persons with CP experience the objectification, alienation and disruption of their bodily experience or that they experience a diminished sense of agency or lack of control, despite undergoing spastic movements. Instead, they experience their body as something they have control over and are certain of, but the way in which they experience this comes about by exerting control.

### 5.3 Musical Absorption

For Høffding, the second tier began with the transcription of statements from tier one and the generation of phenomenologically relevant categories. From the transcriptions, detailed descriptions were favoured and heavily opinionated statements bracketed. Non-essential material such as aspects of the interviews that strayed completely from the topic was not included in the categorized version. Through the process of selection and categorization, the entire transcription was reorganized, condensed and thus more amenable to establishing a clear overview of the large data-set. Key categories contained passages on reflection, deep absorption (or "being in the zone") and an altered sense of self, which could be used as a factual variation to the claim that reflection impedes coping (for more methodological details, see Høffding & Schiavio, forthcoming). This work initiated a series of analyses, philosophical reflections, discussions, and the writing of several drafts. In Høffding's case, part of the interview material could efficiently be set up against Dreyfus' framework to expose a number of problems. Over three years of working on several drafts regarding different aspects of the phenomenology of expert musicianship, re-categorizing and re-conceptualizing material from tier one, presenting the material in numerous workshops and conferences and receiving feedback from several academics, Høffding could make a number of warranted and coherent conclusions, some presented in Høffding (2014). As mentioned, it cannot generally be accepted that reflection obstructs coping: rather, Høffding's work revealed that the very notion of "coping" is in fact spurious with no definite referent, because all but a very few mental states experienced while performing include an aspect of coping. Also, Høffding's initial preconception of a selfless intentionality seemed to be misguided. Rather, the interviews indicate that deep absorption is marked by a profound change in the sense of agency and self-awareness, which leads to difficulty in self-ascription during deep absorption.

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<sup>27</sup> See chapter 4 in this Ph.D. dissertation.

The idea that deep absorption, rather than a complete lack of self-awareness, is an expression of a profound change in self-awareness has a high degree of internal phenomenological consistency because the DSQ's statements with respect to absorption can be understood on this interpretation, which is in contradistinction to Dreyfus's model. In terms of external phenomenological consistency, Høffding's research thus puts pressure on Dreyfus' model of coping and the folk-psychological notion that one shouldn't think too much while performing. On the other hand, it preserves the phenomenological key idea from Husserl, Sartre, Merleau-Ponty and Zahavi that all awareness has an element of self-awareness and is in line with suggestions from Legrand and Ravn (2009), Montero (2010; forthcoming) and Sutton and Geeves (Sutton et al. 2011; Geeves et al. 2013).

## 5.4 Summing up: Phenomenological Interview and EI

We share with EI the idea that one can develop an interview methodology that gives access to the pre-reflective structures of consciousness. We also share many of the specific pragmatic techniques of the interview. The main difference concerns the possibility of re-enacting an experience. Due to our phenomenological commitments, we do not consider this a viable solution, and this difference leads to changes in the aim of the interview and its subsequent interpretation. Instead, we highlight the reciprocal nature of the encounter and the co-generation of descriptions. This again leads to a conception of validity that places increased weight on the interpretative nature of the second tier. Impressively, EI can induce an increased self-awareness such that epileptic patients can learn to anticipate their seizures (Petitmengin et al. 2007). Contrastively, the phenomenological interview can do no such thing. It does not have a therapeutic, psychological or existential aim as such, but is a research tool to enhance the scope of phenomenology as a factual variation.

## 6. Conclusion

To conclude, we think that this process, which is built over two methodologically distinct, but overlapping processes, can guarantee the phenomenological value of an interview. The interview is informed by four principle phenomenological commitments, namely:

- 1) To the thing itself: using the interview to acquire detailed first-person descriptions of an experience in question.
- 2) Invariant structures: Using the interview to grasp the invariant structures of experience.
- 3) Subjectivity cannot be reduced to objectivity: In the interview, the first-person perspective needs to be understood on its own terms.



4) Enaction, embodiment and embeddedness: Phenomenology construes subjectivity as embodied, enactive and embedded. The interview directly confronts us with these aspects of experience.

Tier one might seem simple but, in fact, the very interview relies on one's training and concentration as an interviewer, as well as years of prior phenomenological training. One must be empathetically present with the interviewee and at the same time consult one's phenomenological background knowledge to generate descriptions that are as detailed and clear as possible. Tier two is an extension of tier one in which one employs the skillset from phenomenological analysis such that the tiers are in epistemological continuity. One can easily spend years going back and forth between the two tiers before one is satisfied and can judge whether one's grasp of the interpretations and conclusions drawn from the interview is phenomenologically consistent.

We have set out the "what, why and how" of the phenomenological interview. We have yet to answer the "where" question. In other words, where is this interview applicable? As mentioned, it is certainly not relevant to engage in a demanding interview, if one wishes to conduct classical phenomenology. But, as soon as one ventures into fields informed by empirical analysis and especially those that target experiences that are not available to one's own first-person perspective, the phenomenological interview becomes relevant. The fact that the framework presented can encompass and shed light on two cases as different as the pathology of cerebral palsy and expert musicianship testifies to its versatility and wide potential applicability. Other fields that could also benefit from our methodological reflections include, as mentioned, those inquiring into expertise, athletics, meditation, various illnesses and pathological conditions, and the education of nurses, doctors, psychologists and architects. We also believe that research projects such as Gallagher's on astronauts (Reinerman-Jones et al 2013; Gallagher et al 2014) and Thompson's on dreamless sleep (2014) could benefit from our work.

On a final note, we suggest a serious interdisciplinary effort, and encourage colleagues potentially interested in this approach to phenomenology to work with trained interviewers from for example sociology, anthropology or ethnography. We hope that such collaboration will lead to further reflections on the combination of interviews and phenomenology.<sup>28</sup>

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<sup>28</sup> This article is to a large extent based on tutoring from, and extended conversations with Dorothée Legrand and Susanne Ravn. We are indebted to them for their support, inspiration and critical conversations throughout the process of writing the article. We also wish to thank Claire Petitmengin for an extended discussion and demonstration of some elements of the fascinating EI technique, Dan Zahavi, Shaun Gallagher and John Sutton for comments on earlier drafts as well as the Center for Subjectivity Research, the Section of Philosophy, Department of Media, Cognition and Communication, University of Copenhagen, and the MacNap workshop at the Department of Cognitive Science at Macquarie University for critical discussions during presentations of earlier drafts of the present paper. Finally, thanks to one anonymous reviewer for helpful points and to Adele Jourdan for proofreading the article.

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## Part II

# A Case Study of Cerebral Palsy: Embodied Control and Certainty

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## Chapter 4

### How to develop a phenomenological model of disability

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# How to develop a phenomenological model of disability

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## Abstract

During recent decades various researchers from health and social sciences have been debating what it means for a person to be disabled. A rather overlooked approach has developed alongside this debate, primarily inspired by the philosophical tradition called phenomenology. This paper develops a phenomenological model of disability by arguing for a different methodological and conceptual framework from that used by the existing phenomenological approach. The existing approach is developed from the phenomenology of illness, but the paper illustrates how the case of congenital disabilities, looking at the congenital disorder called cerebral palsy (CP), presents a fundamental problem for the approach. In order to understand such congenital cases as CP, the experience of disability is described as being gradually different from, rather than a disruption of, the experience of being abled, and it is argued that the experience of disability is complex and dynamically influenced by both intrinsic and extrinsic factors. Different experiential aspects of disability— pre-reflective, attuned and reflective aspects—are described, demonstrating that the experience of disability comes in different degrees. Overall, this paper contributes to the debates about disability by further describing the personal aspects and experience of persons living with disabilities.

Keywords: Experience of disability, Embodiment, Illness, Normality, Motor intentionality, Phenomenology

## 1. Introduction

During recent decades, various researchers from health and social sciences have been debating what it means for a person to be disabled. These debates have primarily been dominated by advocates of the so-called *medical* and *social model*. The former model sees disability as a dysfunction, disturbance, disorder or abnormality of the health condition of the individual and of normal homeostasis. Disability is therefore defined as a result of the physical conditions of the individual and as a property intrinsic to the individual. By contrast, the social model acknowledges that dysfunctions, disturbances or disorders in a person's health condition may cause limitations, but it stresses that the key disabling factor is in fact societal features. It's the social barriers and the negative and excluding attitudes in society that impose disability on the individual. Being disabled should therefore be understood as an extrinsic property.

In contemporary debate, the two models have come to represent two oppositions in a discussion of disability. However, more and more researchers acknowledge that being disabled should be understood as a complex, dynamic and multidimensional phenomenon (Leonardi et al. 2006; Shakespeare 2006; Forsyth et

al. 2007; Smith 2009). A new attempt by The World Health Organization (WHO) has equally defined disability not simply as a matter of either intrinsic physical or extrinsic social factors, but as a complex and dynamic interaction between these and more personal factors, such as motivation and self-esteem. The overall aim is to treat “disability as a continuum rather than categorizing people with disabilities as a separate group: disability is a matter of more or less, not yes or no” (WHO 2011, p. 5. see also ICF 2001).

WHO relates the above personal factors to a person’s participation in society and distinguishes between a person’s capacity to perform actions and their actual performance, in order to highlight the effects the environment has on the person. WHO acknowledges that such personal factors are not yet conceptualized or classified. In order to help clarify the personal factors, it may be beneficial to focus on a fairly overlooked approach for understanding disability. This approach has developed alongside the dominating debate of disability, primarily by effort of researchers inspired by the philosophical tradition called Phenomenology (Zaner 1981; Leder 1990; Toombs 1992, 1995; Svenaeus 1999, 2009; Carel 2008, 2012, 2013a, b; Peckitt et al. 2013). This approach could be called the *phenomenological model* of disability. As a point of departure, it focuses neither on giving physical explanations nor social prescriptions for understanding disability, but precisely on first-person experiences of living with disabilities: what is the experience of being disabled like?

To characterize the phenomenological approach to disability as a *model* is, however, to both overstate and misread the approach. Only a modest number of researchers have taken up this approach, and it could be questioned how much they have intended to contribute to research in disability. These researchers have primarily described the experience of disability while trying to understand what it means to live with illness. The approach has put descriptive effort into understanding disability in a specific transition, namely the transition from the experience of being healthy and able to the experience of being ill and disabled. The underlying claim of the approach is that illness first and foremost represents disability (Toombs 1992, pp. 62–63).

The phenomenological approach to illness addresses some aspects of disability necessary for a phenomenological model of disability. However, in narrowing the description of disability to the transition from healthy to ill, we might restrict ourselves to a specific methodological and conceptual framework, making disability something for which special categories and concepts are reserved. The experiences of a disabled person are typically described as an objectification, alienation and disruption of the lived, healthy and able body, and the embodiment of the disabled is understood as doubtful, problematic and, ultimately, as an inability or ‘I cannot’. In using such a conceptual framework, we run the risk of overlooking other relevant aspects of experiencing and living with disability and of giving a too crude description.

The aim of this paper is to broaden the existing phenomenological approach to disability. To begin with, the methodological and conceptual framework developed from the phenomenology of illness is presented. Then, it’s illustrated how the case of congenital disabilities, looking specifically at the congenital disorder

called cerebral palsy (CP), is a fundamental problem for the framework. In order to understand such congenital cases as CP, the paper discusses methodological and conceptual insights from Maurice Merleau-Ponty, who is typically used in the phenomenological account of illness to support its description of illness and disability. Emphasizing a gradual and developmental understanding of notions such as ‘embodiment,’ ‘motor intentionality,’ and ‘I can,’ a broader phenomenological model of disability is argued for. The experience of disability is described as being gradually different from, rather than disruptive of, the experience of being abled.

In the end of the paper, it’s shown how a broader phenomenological model of disability might help contemporary debates about disability, illustrating the ways in which the experience of disability is a complex and dynamic phenomenon. The experience of disability can be understood as a continuum with different experiential aspects of disability, i.e. the pre-reflective, attuned and reflective aspects, where physical and social factors influence the first-person experience to a greater or lesser extent.

## **2. A phenomenological account of illness**

The primary aim of the phenomenological method is to understand the phenomena in question by grasping them in their meaning or, as the phenomenologist Edmund Husserl famously stated it, by going “back to the ‘things themselves’” (Husserl 2001, p. 168). This means trying to avoid making assumptions about the phenomena beforehand, since these assumptions might be biased by everyday prejudices and presuppositions. The aim is to give direct descriptions of our experience of the phenomena in question.

Contrary to the method of both the medical and social model, a phenomenological model of disability does not aim at giving physical explanations of disability or at focusing on prescriptive aspects of our social understanding of disability. A phenomenological model attempts to understand disability by focusing on what it means to be disabled from the first-person perspective of the disabled person. However, most of the phenomenological descriptions of disability have been conducted while focusing on the experiences of being ill<sup>29</sup> rather than on the experience of being disabled.

### **2.1 First-person descriptions of illness: focusing on the lived body**

The phenomenologist Jean-Paul Sartre famously described the first-person experience of illness, while distinguishing between different levels of experience, namely between ‘pain as lived’, ‘suffered illness’,

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<sup>29</sup> The term ‘illness’ is typically used in the phenomenological literature on illness to refer to more serious, chronic or threatening illnesses, such as multiple sclerosis or cancer. This is also how I’ll use the term in this paper but, as we will see, Sartre and others acknowledge the phenomenological significance of looking at less serious and more common illnesses, such as headaches or the flu.

‘disease’ and ‘disease state’ (Sartre 1969, pp. 331–337, 355–357). At the first level, pain is experienced as disturbing the action I perform and the relation I have to the world. In, for example, reading a book while my eyes are hurting, the pain is not something I’m focused on, since I’m preoccupied with my book, its pages, words and stories. The pain might manifest itself in blurring the words or in a lack of concentration, making me read the same passage several times. At one point I might attend to my pain, either because I’ve stopped reading or because the pain has increased in intensity. At this level, I become reflectively aware of my pain as an object of my attention, which Sartre characterizes as a psychic object. This psychic object, which I apprehend through the pain in my eyes, is what Sartre defines as ‘illness’. At this descriptive level, illness is experienced as an affective object I can endure, hate, find unbearable and disabling, etc. and, thus, as something I suffer from. I might, however, be approached by a friend who starts to question the severity of the pain I have described. At this level, I constitute my illness as what Sartre calls ‘disease’ by including the knowledge and perspective of others concerning the objective nature of my body. In a worst case scenario, I then go to an eye specialist, who, based on my symptoms, explains that I am suffering from the degeneration of my eye lens and an early stage of cataracts. At this level, my pain has become what Sartre calls a ‘disease state’, where the pain is diagnosed by a physician as a medical fact.

Sartre’s description of these different experiential levels and their relations is far more complex and detailed than that illustrated above. Of interest for our purpose are the different conceptual and methodological insights that underline Sartre’s description and that have influenced the phenomenological account of illness. Sartre distinguishes the experience of illness from having a disease, since the latter is conceptualized and objectified through the perspective of another, whether a friend or a physician. There is a clear difference in understanding illness from the perspective of a person experiencing it and from the perspective of another person trying to conceptualize, diagnose and explain it.

In order to capture this difference, it’s fruitful to turn to a basic phenomenological distinction in understanding the concept of ‘body’. This distinction describes two different ways in which I can experience and understand my body, namely as object and as subject, which is usually characterized in German as a distinction between “Körper” and “Leib” (Husserl 1973a, p. 57), and in French between the “corps objectif” and the “corps propre”, or “corps vécu” (Merleau-Ponty 1945, p. 1923). An objective description of the body understands the body from an observer’s perspective, where the observer can be myself, examining my own body in the mirror, or another person, such as a scientist or physician. In taking an objective perspective on the body, we understand the body as something that can be explained, analyzed and defined in, for example, physiological, biological, and anatomical terms.

This is commonsensically how we understand the concept of ‘body’, but the experience of my body as subject, relates to the fact that, while I might observe or attend to my objective body, I do so through my body. In my everyday life, I’m usually not focused on my body and bodily movements when performing

actions, but am instead focused on the world, the projects I engage in and the actions I aim to do. In our daily life, our body is experientially absent (Leder 1990), or transparent, and is something I experience in a tacit, immediate, non-observational way. I experience my body as lived in what can be called a ‘pre-reflective’ way. I engage with the world, and my body is something I live through in order to do so. In other words, I engage in the world while experiencing the world through my body and, in contrast to other physical objects and bodies, I both experience my own body as an object and as lived (Gallagher and Zahavi 2008, pp. 136–140).

Our bodily experiences cannot be described as clear-cut as it might immediately seem from the phenomenological distinctions above. There is a fundamental ambiguity in our bodily experience. In, for instance, touching my own hand, I simultaneously experience my body as both lived (touching) and as object (touched) and, in engaging with other people, I experience them through my body as lived, but I also experience my body as an object for others’ experiences. In the case of being ill, this means that our bodily experience of being ill relates to both lived and objective bodily aspects. It relates to the dysfunction of the objective and biological body, which is typically the focus of, for example, doctors, physicians and biomedical interventions. Biomedicine, however, has a tendency to overlook the lived experience of being ill as seen from the perspective of the patient. In doing so, it ignores a crucial aspect of the experience of being ill, namely the experience of illness-as-lived and, if, as S. Kay Toombs argues, “therapeutic goals are to be optimally effective—and suffering is to be relieved—attention must be directed to the patient’s perceived lived body disruption rather than being exclusively directed towards the objective pathophysiology of the disease state” (Toombs 1992, p. xvi).

Toombs’ suggestion can be seen as characteristic for a phenomenological account of illness. It shouldn’t be taken as a strong claim that biomedicine should be disregarded in dealing with illness, but rather that the patient’s lived experiences should be emphasized and taken as a point of departure. One problem with the suggestion is, nevertheless, that the lived aspects of our bodily experience are difficult to describe and understand. Our experiences of our body as subject are, as mentioned, tacit, non-observational and pre-reflective, which means it might be difficult to understand the way in which illness-as-lived differs from the way we normally experience our body.

However, with illness follows, according to Drew Leder, the pragmatic goal of being relieved from the suffering or of mastering it. This pragmatic goal is closely related to a hermeneutical aspect of self-reflection and of finding out what should be relieved or mastered. In being ill, we engage in self-explorative behavior, trying to figure out the current problem by, for example, reflecting on our bodily history or asking friends or healthcare providers for answers. In doing so, we come to see our body in ways that otherwise would be unavailable or at least overlooked. With illness comes a certain phenomenological and descriptive power (Leder 1990, pp. 78–79).

Havi Carel has recently elaborated on the same point, and argued that looking at experiences of illness is fruitful as a method for describing normally overlooked, tacit and pre-reflective aspects of our experiential life. In the transition from being healthy to becoming ill, an experiential ‘before and after’ becoming ill arises, which creates a differential point of departure for understanding the experience of illness. I can understand my illness in relation to my life before I had the illness and vice versa. Illness is, therefore, a limit case as Carel defines it, where the “displacement from the ordinary destabilizes the structure of experience and reveals our normal way of being by pushing it to its limits” (Carel 2013b, p. 347. See also Svenaeus 1999, p. 108). Carel points out that this already plays a part in Merleau-Ponty’s phenomenological method. Normally, as Merleau-Ponty describes it, we are biased by everyday prejudices and presuppositions we take for granted, but, in using pathological cases, or cases of illness, as a methodological starting point, we can make these biases explicit by putting our normal relation to the world ‘out of play’ (Merleau-Ponty 1962, pp. xiv–xv).

So, what we gain from Sartre’s description above is that, in order to understand illness, we should, in contrast to a biomedical account of disease states, emphasize the experience of the lived body. Furthermore, we see that illness has the phenomenological and descriptive power to precisely highlight these lived aspects, which are normally tacit, overlooked and pre-reflective.

## 2.2. The ill body as disabling

Carel argues that in being ill we experience our body through what she calls ‘bodily doubt’ (Carel 2013a, pp. 188–193). This kind of doubt is a radical modification of three different aspects of our normal bodily experience: (1) loss of continuity, (2) loss of transparency, and (3) loss of faith in one’s body. First of all, we are to large extent habitual and routine beings that function on the basis of the familiarity we experience having with our own body and the world. When we become ill, it’s the continuity of our habitual background that is disrupted and replaced, (Carel 2013a, p. 188. See also Carel 2008, pp. 25–28). The familiarity I had with my body and the world is disrupted in illness to the extent that I experience my body as *un-able* to perform the actions I once did. The possibilities of action are reduced, which means, as Leder says, that “one is actively *dis-abled*. Abilities that were previously in one’s command and rightfully belong to the habitual body have now been lost. This could be termed the phenomenon of the ‘I no longer can’” (Leder 1990, p. 81). Thus, to state the main point of losing continuity in clear terms, let us turn to the words of Toombs: “[f]irst and foremost illness represents dis-ability, the ‘inability to’ engage the world in habitual ways” (Toombs 1992, pp. 62–63).

Secondly, the bodily transparency that characterizes the pre-reflective lived relation we have to our body is highlighted precisely as that which is disrupted and lost (Carel 2013a, p. 191). In illness, one experiences the body not only as an object, as when one perceives oneself in the mirror, but as an object that is

experienced as problematic, alien, foreign, unnatural, or dysfunctional, all of which can be captured by Leder's notion of 'dys-appearance':

[i]n contrast to the 'disappearances' that characterize ordinary functioning, I will term this the principle of *dys-appearance*. That is, the body *appears* as thematic focus, but precisely as in *adys* state – *dys* is from the Greek prefix signifying 'bad', 'hard', 'ill' (Leder 1990, p. 84).

Thirdly, the loss of both continuity and transparency is related to a loss of the experience of certainty that we have of our body and actions (Carel 2013a, p. 192). In being ill, we start to question whether or not we are able to perform actions we normally do. A bodily distrust has found its way into the heart of our daily life, reducing our possibilities for actions. We find ourselves disabled. Performing actions may now require detailed planning, a lot of effort and might be accompanied by the experience of, for example, anxiety.

The experience of illness can therefore be related, as Frederik Svenaeus (1999, pp. 156–157) does, to the way in which the phenomenologist, Martin Heidegger, describes the 'uncanny' (*unheimlich*) feeling of not-being-at-home in the world (Heidegger 1986, p. 188). Svenaeus describes this feeling by relating the experience of our body to that of a broken tool. In doing so, he's not arguing that our body should be understood as a physical tool, but he's emphasizing that, when a tool is broken, so is the contextual relation it has to the world, namely the actions and activities that were once possible to do with the tool. In relation to the experience of our body as ill, it means that the world we once experienced as meaningful, homelike and complete with action possibilities has broken down. In being ill, we experience a disruption of the world we once inhabited, the actions that were once possible and the way we were in the world. It's a fundamental breakdown of our experience of being-in-the-world (Svenaeus 1999, pp. 108–112).

So, the main insight and an important strength of the phenomenological account of illness is to show that, in order to understand illness, it's not sufficient to only look at the body as a target for biomedical intervention.<sup>30</sup> In the description of disability, this insight translates into a focus on bodily doubt, which means that disability is understood, as Carel says, through "the transition from health (bodily capacity) to illness (bodily incapacity), via the experience of bodily doubt" (Carel 2013a, p. 187). This focus presents us with descriptions of an explicit period of time in illness, the transition from healthy to ill, emphasizing the disruption of the lived body. But how does the phenomenological approach address the developmental aspects of having learned to live with the disabilities associated with chronic illnesses, or with congenital disorders, if the conceptual framework is built up around the transition from healthy to ill?

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<sup>30</sup> Thanks to the reviewer for illustrating the need of making this point more explicit.

### 2.3. Living with congenital disability

Not all cases of disability have a ‘before and after’ becoming ill, i.e. a disruption of a familiarity, continuity and normality making the experience of disability stand out. This is, for instance, the case for congenital disorders where the experience of being disabled is the norm, the case of chronic illness, where the ill have learned to live with their illness, or the case where we might be considered disabled by our gender, since our gender structures the way we normally experience the world (Young 2005). In narrowing the descriptions of disability to illness, and using a picture of healthy and normal behavior or functioning as our starting point, we run the risk of overlooking certain aspects of experiencing and living with disability.

In conducting research on the congenital disorder called cerebral palsy (CP), 14 persons (7 women, 7 men, age 23–57) were interviewed in order to understand what it means to experience and live with congenital disability. The interviews were done over a period of 1 year and took place at the Helene Elsass Center (HEC), a Danish center working primarily with CP. The participants were part of a (re)habilitation project, focusing on the effects of intensive strength training. Out of the 20 participants taking part in the strength training project, 14 participants were selected for the interviews by focusing on the most common type of CP, spastic CP. The 14 participants represent the diversity of spastic CP to a great extent, since the group included participants with a diverse range of bodily impairments and with different degrees of severity of such impairments. In relation to the gross motor function classification system (GMFCS) developed for children with CP, the participants in the study correlate to Level I–IV (Palisano et al. 1997). Descriptions from the interview that are of interest to the topic of this paper will be presented, which means descriptions from 6 out of the 14 participants.

The overall design of the interviews and the analysis is inspired by phenomenological research, which uses semi-structured interviews as a methodological technique (e.g. Varela and Shear 1999; Vermersch 1999, 2009; Petitmengin-Peugeot 1999; Petitmengin 2006; Petitmengin and Bitbol 2009). The interview design of this study of CP won’t be further elaborated, since the aim of this paper is to discuss the overall methodological and conceptual framework for giving phenomenological descriptions of the experience of disability and to, thereby, understand what it means to be disabled. For elaboration on the methodological issues of the study, see Høffding and Martiny (forthcoming).<sup>31</sup>

CP is typically defined as a group of disorders in the development of postural and motor control, occurring as a result of a non-progressive lesion of the developing central nervous system (Bax et al. 2005). However, in being interviewed, all of the participants pointed to the same descriptive problem, namely, as TV, a 28-year-old man with spastic diplegia, explains it:

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<sup>31</sup> See chapter 3 in this Ph.D. dissertation.



[l]iving with CP...that's difficult to describe, because I've never tried anything else. In other words, what I experience I've always experienced. I think it's easier to say something adequate if you have been involved in for example an accident or something else, but I haven't. I was born nine weeks premature, which means, I've only experienced what we could call progress. I've only progressed in my life. So what we can say of me, or people like me, is that the most apparent difference is that we're born with poorer preconditions... This is the world I'm born in and these are the preconditions I've always known.

This description implicitly points to the tension, as highlighted by the phenomenological account of illness, between first-person experiences of living with disability and biomedical explanations of it.<sup>32</sup> Although TV explains that he was born premature and with poorer preconditions, this should be understood within a biomedical framework, which suggests a lack of progress in the development of postural and motor control. TV describes that he doesn't experience a lack of progress, since this is the way he was born, this has been his developmental point of departure and, therefore, he has only experienced progress in his life.

Thus, in order to understand what it means to live with CP, we should, as suggested by the phenomenological account of illness, focus on the experience of the lived body. This experience, however, is closely related to the developmental aspect of CP and is the reason why persons with CP don't experience things being different. MP, a 31-year-old woman with spastic paraplegia, says that "I don't think that I've thought that much about something being different. It probably has something to do with the fact that when you have learned something, then that's the way you are going to do it." MS, a 26-year-old man with spastic hemiplegia in his left side, describes this point further by relating the way he acts to the way he believes people normally act:

[m]y body does what I want it to do and I know the actions that are difficult. I can act before they happen, before it becomes a problem. But it's a question of degree...I have to correct my movements, when something unexpected happens, but everybody has to do that. I just have to do it to a much larger degree.

MS is clarifying that there is only a gradual difference between the way that he acts and the way he believes we normally act. The question is then: how should we understand cases like that of a person living with a congenital disability, if the difference between the way in which he acts and the way in which we normally act is only a matter of degree?

One could answer this question by holding on to the conceptual framework developed from experiences of illness and by, therefore, acknowledging, as Carel does, that "[b]odily doubt can also diminish as one adjusts to certain incapacities (e.g. in certain forms of disability) and may be completely absent in the case of congenital disability" (Carel 2013a, p. 187). In congenital disabilities, people have not experienced any

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<sup>32</sup> Thanks to the reviewer for making me aware of this implicit point in the description.

transition from health to illness and, therefore, they “are in most cases not in unhomelike attunements of illness”, as Svenaeus would describe it, since “they perform their activities in a way that makes sense to them in their life” (Svenaeus 1999, p. 188). However, adopting such descriptions of congenital cases like that of CP wouldn’t do such cases justice. The different descriptions above show that the experience of being disabled in CP doesn’t necessarily relate to the experience of having bodily doubts and being in unhomelike attunements. This doesn’t mean, however, that the persons with CP don’t experience themselves as disabled. HJ, a 48-year-old spastic paraplegic, describes his experience of being disabled in the following way:

[t]here is always an element of constant adjusting. It’s difficult to explain. Call it reaction, which is that I have to react against my own body. It’s like the difference between if you walk normally and if you walk with weights on your feet. I just don’t have anything to compare it to, since I haven’t had the weights off my feet. I can just see that everything is more difficult for me than for everyone else. ...Typical daily tasks just take more time, either because I have to do it in a different way than you do or because I become tired more easily than you.

HJ emphasizes that there is a difference between how he walks and how he believes we normally walk. One might therefore argue that it must be possible to understand CP and congenital disability in general by comparing the phenomenology of congenitally disabled with the normal phenomenology of the non-disabled.<sup>33</sup> One problem with this approach, as will be made clear below, is to understand the relation between normality and disability in a more complex way than differentiating the experience of being healthy and able from the experience of being ill and disabled. As Merleau-Ponty argued, we should understand that “the blind man’s world differs from the normal person’s not only through the quantity of material at his disposal, but also through the *structure* of the whole” (Merleau-Ponty 1962, pp. 261).

### 3. The structure of the whole: the ‘I Can’

So far, I have argued that describing disability as the experience of illness, as a bodily doubt, and as disruptive of the lived body, is not sufficient. In the following, I’ll describe aspects of our underlying structure of embodiment that are relevant for understanding the experience of disability. I’ll do so by discussing methodological and conceptual insights from the work of Merleau-Ponty, who is typically used in the phenomenological account of illness to support its descriptions of illness and disability.

#### 3.1 An intentional analysis of disability

In Merleau-Ponty’s first work, *The Structure of Behavior*, he questions what method to use in order to understand cases of illness and concludes that illness

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<sup>33</sup> Thanks to Shaun Gallagher for raising this point (personal conversation).

does not directly concern the content of behavior but rather its structure and consequently that it is not something which is *observed* but rather something which is *understood*. The conduct of the patient is not deduced from the conduct of the normal person by simple subtraction of parts; it represents a *qualitative* alteration (Merleau-Ponty 1967, pp. 64–65).

Merleau-Ponty criticizes the way of making sense of illness by observing, subtracting and isolating parts of the content of the ill person's behavior, i.e. what the person does, and by subsequently contrasting it with the behavior of a normal person. According to Merleau-Ponty, the right method to use consists in a new kind of analysis that treats both ill and normal behavior as qualitative alterations.

Merleau-Ponty goes on in his second work, *Phenomenology of Perception*, to further explain what he means by this new kind of analysis. It shouldn't be seen as a classical inductive method, where the normal can be inferred from the ill, and vice versa, by a change of sign, making illness the abnormal. It should also not be seen as a causal mode of explanation, since it isolates variables that are either present in the normal case or absent in the case of illness. According to Merleau-Ponty, the method we should use in order to understand cases of illness "is not a 'differential method'; it consists in correctly reading phenomena, in grasping their meaning, that is, in treating them as modalities and variations of the subject's total being" (Merleau-Ponty 1962, pp. 123–124). In contrasting the normal and the ill, we should be searching for something more fundamental, namely, the structures of our existence. Merleau-Ponty calls the method for making these structures explicit *existential* or *intentional analysis* (Merleau-Ponty 1962, pp. 127 and 68).

The primary function of intentional analysis is, first of all, the "making explicit or bringing to light of the prescientific life of consciousness which alone endows scientific operations with meaning and to which these latter always refer back" (Merleau-Ponty 1962, p. 68). Thus, if we aim to understand disability, we cannot, as already shown, take scientific explanations of, for example, physiological dysfunctions or disorders as a point of departure since, as Merleau-Ponty states, "[t]he living physiology of the nervous system can only be understood by starting from phenomenal givens" (Merleau-Ponty 1967, p. 88). Secondly, we should also not base the method for understanding disability on illness as a limit case, since intentional analysis is, as mentioned above, more complex than a differential method. It consists in correctly understanding the phenomenon of being disabled or ill as a variation of the subject's total being.

### 3.2 The developmental relation between the actual and habitual body

Besides being careful with the method we use, it is of equal importance that we also question our conceptual framework and, if necessary, either re-define existing concepts or develop new ones. This is especially crucial when it comes to our understanding of the 'disabled body' because, in this case, it becomes clearer, as Merleau-Ponty says, that "there are *several ways for the body to be a body, several ways for consciousness to be consciousness*" (Merleau-Ponty 1962, pp. 142–143).

Merleau-Ponty looks at the case of phantom limb experiences to understand what it means for the body to be a body. This case involves a sensation, for example a painful, itchy or tickling sensation, felt in a body part that has been amputated. What is puzzling about this case is that it shouldn't be possible to experience sensations in a body part that is no longer there. The afferent nerves in the limb that carry signals towards the brain don't exist. Thus, it's not sufficient to give a physiological explanation of why the person is still able to experience the limb. It could still, however, be the case, as Merleau-Ponty points out, that what is present is a representation of the limb, or one could give a psychological account of the phenomenon by claiming that it is in fact a memory that the person has of the limb (Merleau-Ponty 1962, p. 87–89). Yet this doesn't give us a clear understanding of the phenomenon since, as Merleau-Ponty says in the case of a person with a phantom leg:

if he treats it in practice as a real limb, this is because, like the normal subject, he has no need, when he wants to set off walking, of a clear and articulated perception of his body: it is enough for him to have it 'at his disposal' as an undivided power. (Merleau-Ponty 1962, p. 93)

Merleau-Ponty argues that the limb is neither represented nor remembered but actually 'present' in an ambivalent way, which is somewhat similar to the way in which the normal subject experiences his limbs. In both cases, the leg is experienced as lived transparently and as simply being at one's disposal for walking—as "absently available" (Gallagher 1986). Thus, the reason why it is possible to experience the phantom limb as if present is because to "have a phantom arm is to remain open to all the actions of which the arm alone is capable; it is to retain the practical field which one enjoyed before mutilation" (Merleau-Ponty 1962, p. 94).

According to Merleau-Ponty, the case of phantom limb experiences illustrates that our body is a compromise between two distinct layers, which he calls the *actual-body* and the *habit-body* (Merleau-Ponty 1962, p. 95). The latter refers to the habitual aspects of our lived bodily experience and illustrates that, in performing many of our daily actions, we don't attend to our bodies. Throughout our life, we have learned many bodily skills, which we reinforce every time we perform actions that require such skills. This means that, in performing actions, we are able to focus on the goals of our actions while relying on our bodily repertoire. The habitual body is the background for performing many of our daily actions but, in order to do so successfully, we also need instant feedback from the environment and from our body at this moment, our actual-body. We need, for instance, kinesthetic and proprioceptive feedback in order to be able to act in accordance with the environment and to do so appropriately. The actual and the habitual body typically go hand in hand in our daily life, but it is possible that they can come apart, as in the case of phantom limb experiences. In this case, the habitual body is still part of the lived experience of the person, since the environment affords actions possible for the habitual body, but the experience doesn't accord with that of the actual body.

Merleau-Ponty's understanding of the case of phantom limb experiences may seem clear and convincing from the outset, but research into this phenomenon (e.g. Gallagher and Meltzoff 1996) points to the fact that phantom sensations can also occur in cases of congenital absence of a limb (aplasia). How is it possible to understand cases of aplasia in Merleau-Ponty's framework, if there is no dissolution between the actual and habitual body? The limb has never existed, so why would the person experience a phantom limb?

The interpretation of aplasia is not at all straightforward. Should aplasia be understood by arguing for innate neurophysiological preconditions, or by arguing that it's a result of acquired personal and social features (see Gallagher et al. 1998; Gallagher 2005)? In introducing the case of aplasia and raising critical doubts concerning Merleau-Ponty's framework, I'm not going to choose a side within the debates regarding aplasia. I'm merely using aplasia to illustrate the point that there is a more complex relation between the actual and habitual body than initially illustrated by Merleau-Ponty. In fact, if we aim to understand the relation between our actual and habitual body, and thereby understand the experience of disability, we need to address the preconditions we have for developing this relation. Insofar as we develop, for instance, our bodily capacities and habits throughout our life, we do so within the limits and predispositions of our bodily abilities and disabilities. This is a common structure of abled, as well as disabled, persons, and it relates to the fact that, as Merleau-Ponty acknowledges in relation to the case of phantom limb experiences,

[t]he body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them (Merleau-Ponty 1962, p 94).

However, to be in the world and to define projects to which we are committed clearly depends on what is in fact possible for us to do, i.e. on what we *can* do.

### 3.3 Embodiment comes in degree

Merleau-Ponty expands his description of the underlying structure of embodiment by developing a new concept, since the concepts available for understanding the body, and its movements and behavior, in scientific explanations (e.g. muscles, bones and nerves) and in traditional psychology (e.g. representation) are not able to clarify such cases as that of phantom limb experiences. He introduces the concept of 'motor intentionality,' which describes the body, behavior and movements, as comprising something between third person mechanistic processes and intellectualistic representation (Merleau-Ponty 1962, pp. 126–127).

Merleau-Ponty defines motor intentionality as the way in which we primarily are in the world, a way in which our experience of the world and its objects are structured through our possible actions and potential movements. The world shows itself, and we perceive the objects within it as 'poles of actions' (Merleau-Ponty 1962, p. 122), which means that we experience the world as having a value or meaning for us in terms

of our interaction with it. This value is both defined by the actual situation we are in (actual-body) and our bodily capacities to deal with this situation (habit-body), but also by the movements and actions we *can* make and the situations and stimuli that are possible for us to experience. Our experience of the world is therefore structured through a background made up of our habits, bodily skills and ordinary engagement with the world, but an important part of this embodied relation is the ability for us to turn away from the world and to reflect on this background. Thus, being embodied in an actual situation means also being able to withdraw from the world and to take an abstract stance towards the world and towards what is potentially possible for us to do. It means that we are able to ‘reckon with the possible’ (Merleau-Ponty 1962, p. 125).

One problematic aspect with Merleau-Ponty’s concept of motor intentionality is that, in the analysis of the famous Schneider case, several researchers have emphasized that Merleau-Ponty claims that motor intentionality is both lacking and preserved. I’m not going to describe the case of Schneider here. Instead, I will emphasize that a charitable reading of the case would argue that Schneider has a pathological mode of motor intentionality and that, therefore, such motor intentionality is neither lacking nor preserved, but lies somewhere between the two (Dreyfus 2007, pp. 63–64, 69; Jensen 2009, pp. 385–397). Merleau-Ponty acknowledges in a few places that motor intentionality is not a question of either/or, but a matter of degree (Merleau-Ponty 1962, pp. 140, 143, 154). I suggest that endorsing a gradual and developmental understanding of motor intentionality will help us describe what it is to live with congenital disability.

Living in accordance with one’s own body requires an understanding of what Merleau-Ponty, following Husserl, calls the ‘I can’ (Merleau-Ponty 1962, p. 159; see Husserl 1989, pp. 269–289), which can be described as an understanding of “the harmony between what we aim at and what is given, between the intention and the performance - and the body is our anchorage in a world” (Merleau-Ponty 1962, p. 167). This understanding is not knowledge in the classical sense of ‘I think that,’ but is based on the harmony between the development of the habitual body, the performance of the actual body and our experience of the possible field related to our specific action, i.e. our ability to ‘reckon with the possible’. This is how Merleau-Ponty would describe motor intentionality but, in the case of the phantom limb, the “I can” is disrupted due to a change in the actual body along with the persistence of the habitual body and its field of action possibilities. In the case of illness, as we have seen, the habitual body and the field of action possibilities are also disrupted, increasing the focus on the actual body as a dys-appearing object. These two different cases of disability illustrate two different modes of experiential disruption of the lived body and of motor intentionality, where the experiences of disability may be characterized as instances of illness, or examples of ‘I no longer can’ or ‘I cannot’.

People living with congenital disabilities don’t necessarily experience such disabilities as examples of ‘I no longer can’ or ‘I cannot’. In these congenital cases, as in the way we normally experience our body, our field of bodily action is structured by our actual body and its (dis)abilities. For example, we are not able to

fly, jump over a tall building, or perform an action that our lack of ability prevents us from doing, such as being able to see in the case of congenital blindness. The reason why people living with congenital disabilities don't necessarily experience their disabilities as a form of illness is because they have developed their field of action according to their bodily (dis)abilities. It is a common structure for abled as well as disabled persons that our perspective on the world, our field of action, and our intentions are structured in accordance with our bodily abilities and disabilities—with the “I can” (or “I cannot”) as it is defined for each individual. This should in fact be seen as the core of the concept of ‘motor intentionality’ because, as Merleau-Ponty says, “our intentions find their natural clothing or their embodiment in movements and are expressed in them as the thing is expressed in its perspectival aspects” (Merleau-Ponty 1967, p. 188). Thus, there is an underlying common embodied structure for both abled and disabled experiences.

## 4. A complex understanding of disability

The medical and the social models in the disability debates raised questions as to whether we should understand disability as an intrinsic or an extrinsic property. Based on the phenomenological understanding of embodiment as a matter of degree, I'm going to argue that the personal experience of disability is a complexity of both intrinsic and extrinsic factors and that there exist different ways to experience disability, where these factors influence more or less our first-person experience of disability.

### 4.1 The experience of disability as both intrinsic and extrinsic

We might be born with physiological dysfunctions, or disorders, which might subsequently become disabling for us; however, we don't initially experience these aspects as disabling. When we are born, we don't experience being disabled, since everyone experiences themselves and their (dis)abilities as their own normal point of departure. Husserl clarifies this point by emphasizing that we are all born into this world with an initial self-primacy and that, therefore, one's lived body and experience of the world cannot at the outset appear as abnormal, pathological or disabling from a first-person perspective: “I have, in the first place, normality within my solitary ego” (Husserl 2008, p. 649).<sup>34</sup>

Nevertheless, we don't develop our ‘I can’, i.e. our intentions, performances and field of possible actions, in a closed, individual vacuum. From the time we are born, we are already part of a social environment, and we develop throughout our life within a cultural setting and with the help of parents, family, friends,

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<sup>34</sup> Translated from German by J. Taipale (2012: 54): “Ich habe als Erstes Normalität innerhalb meines solitären Ego”. Thanks to Taipale (personal conversation) for alerting me to this Husserlian point of distinguishing between two kinds of normality.

teachers, etc. We are born into what Husserl calls an ‘intersubjective normality’, which we habitually and gradually adjust our lives to (Husserl 1973b, pp. 17, 20). This kind of social normality might differ from culture to culture and, in some instances, it can create social barriers, display exclusionary and negative attitudes towards us, and lead to the experience of being disabled socially.

However, that we are born into social normality doesn’t justify the conclusion that disability is solely an extrinsic property. It doesn’t change the fact that my experiential possibilities are structured and developed in accordance with my individual point of departure, for example, the limits of my own body and its abilities. After realizing the social abnormality of her disability, a congenitally blind person may experience her physiological disorder as abnormal, insofar as she is unable to have visual experiences like everyone else. But, even if she knows that other people have visual perception, she is still not able to see, and she doesn’t have experiential access to this visual dimension. This means, as Joona Taipale argues, that her experience of the world cannot include the experience of the actual *lack* of visual perception (Taipale 2012, p. 58). So, in one (social and external) sense, she might experience herself being abnormal and disabled but, in another (individual and intrinsic) sense, she doesn’t, since her developmental point of departure has constituted a specific way for her to experience the world. Nevertheless, part of her experiencing herself as socially and externally disabled is due to her congenital blindness. This means that, while both intrinsic and extrinsic aspects influence her experience of disability, not every aspect of her life is fundamentally experienced as abnormal.

It’s therefore crucial to keep in mind that when we develop throughout our life, individually and socially, we do so within the limits of our own biological body and its abilities, both actual and possible. So, in one sense of the concept of ‘disability,’ everyone is disabled, since we aren’t able, for example, to live without breathing, to be invisible, or to experience the synaptic transmissions of our brain from our first-person perspective. This holds true for everyone. This sense of disability is banal and, on an experiential level, relies on a misunderstanding of the ‘I can’. If I experience myself as disabled, because I cannot, for example, live without breathing, I haven’t fully understood the correlation between my intentions, performances and field of possible actions. Normally, however, we don’t experience being disabled in this sense, since we have in fact spent an enormous amount of time and effort to develop our own body (both actual and habitual) and to create an understanding of our bodily abilities and field of actions. This developmental description is equally true for people living with congenital disabilities but, whereas we normally rely on the habitual body to make the actual body transparent, people living with congenital disabilities have, depending on their specific disability, a different relation between the actual and habitual body and, therefore, a different embodied relation to the world.

In order to understand the ways in which we experience ourselves as being disabled, or not, we must first of all acknowledge that disability is both an intrinsic and extrinsic property. The experience of disability is



structured within the limits of our physical and social conditions, and depends on how we develop personally in accordance with these limits. There is, therefore, not one disabling factor, but a complexity of factors, all of which are related to the ways in which we experience being disabled from a first-person perspective. The phenomenological approach to disability shouldn't, therefore, be seen as a model in contest with the medical and social models. By including the first-person lived experiences of people with disabilities, the phenomenological model aims to strengthen the view that disability should be understood as a complex, dynamic and multidimensional phenomenon. The model shows that it's possible to experience different levels of disability, depending on both physical and social factors.

#### 4.2 Experiential aspects of disability

I have presented different experiential descriptions of disability throughout this paper and have argued that they may arise due to various physical, personal and social conditions. We saw in Sartre's description above a case of what I would call *pre-reflective experiences of disability*, where pain is experienced as a disabling part of an action I perform and the relation I have to the world. Other similar minimal experiences of disability might include being tired, having a headache or other minor physical disabilities in our daily life, all of which pre-reflectively influence our intentions, performances and field of action. Social conditions may also give rise to such pre-reflective experiences of disability by creating social barriers that impose limitations on the actions I perform, the intentions I hold, and the field of actions I have.

I have also described cases of what I will call *reflective experiences of disability*, such as in the case of illness. These severe experiences of disability might occur due to physical conditions, which severely limit my daily life, but also occur in social settings, where, due to, for example, an illness we suffer from, we are excluded socially and experience ourselves as being abnormal. The experience of disability in the case of congenital disability can in some aspects be described by emphasizing these reflective experiences. However, as argued in the case of congenital blindness, not all experiential aspects of living with congenital disability have these features. Should we then describe these aspects as pre-reflective experiences of disability?

By introducing the concept of 'lived, bodily discomfort', Svenaeus has recently tried to describe an experience of being disabled pre-reflectively. His account differs from the way in which such experience was described above, in that it goes beyond the minimal case of 'pain as lived' (Svenaeus 2009, p. 62). I support the attempt to introduce another aspect of the pre-reflective experience of disability, but I disagree, as already argued, with the conceptual framework on which such an attempt is based, namely, that according to which illness first and foremost represents disability. Experiencing the lived body as disabled in cases of congenital disabilities does not necessarily mean experiencing it as discomforting, or for that matter problematic, alien, foreign, etc.

I propose to adopt a conceptual point of departure presented by Dorotheé Legrand, namely that it's possible to experience my lived body in terms of a pre-reflective experience *of* the body, rather than as something that is wholly transparent to me (Legrand 2007, p. 500). Legrand calls this experience of the body the 'performative body,' and describes this notion in relation to the 'transparent body', i.e. the pre-reflective bodily experience of the world. She distinguishes between the two by giving an example of expert dancers. After a long period of extensive training expert dancers are able to perform skillful dancing without attending or observing their bodily movements, which indicates the transparency of the body. In improvised dancing, the dancers attune to their body in a way that gives them the ability to create a dance out of the movements possible for them at every different moment throughout the dance. They rely on their learned skills, but attune to their actual possibilities for movement and action. In this creation, as Legrand says, "goal and means collapse to some extent, and the experience of the body and its morphocinetic actions come 'at the front'" (Legrand 2007, p. 502).

Legrand clarifies her description by borrowing a notion already introduced by Gallagher (Legrand 2007, p. 501), namely the notion of 'pre-reflective pragmatic self-awareness' (Gallagher 2005, p. 46). This form of pre-reflective self-awareness is, according to Gallagher, "tied to my embodied capabilities for movement and action" (Gallagher 2005, p. 74) and here bodily self-awareness is not described "in terms that are explicitly about body parts, but in terms closer to the goal of the action" (Gallagher 2005, p. 73). What Gallagher suggests is that describing the performative body and how the body is 'at the front' of experience doesn't mean describing the body or its part as an object of experience. The latter experience can be defined as where the body is 'in front' of the experience, but when the body is 'at the front' of the experience the body is still experienced as subject. While performing the improvised dance the body is experience as subject, but with an attuned awareness.

Another aspect of experiencing disability is therefore what I would call *attuned experiences of disability*, in which the body is 'at the front' of the experience, not necessarily as something discomforting or as an object, but, rather, as something in which one constantly attunes to the actual possibilities for movement and action while engaging with the world. Here, motor intentionality is tied to the actual possibilities for movement and action. This is how I would describe certain experiential aspects of people living with congenital disabilities, namely that they are attuned to their actual body and field of action while engaging with the world. Their body is not 'at the front' of their experience by choice, as in the case of the expert dancers. They experience their body as requiring a focused awareness, drawing their attention away from the world, but it's nonetheless something that they have attuned to and learned to live with.

In one research interview on cerebral palsy, NJ, a 25-year-old man with spastic tetraplegia, describes his attuned experience of disability, while giving an example of how he walks:

[i]t's not because we [people with cerebral palsy] think about everything, but we just use more energy and strength to think about, for example, not falling or looking at where we're going. I'm not good at compensating when I walk, because I use extra strength not to fall between the bike lane and the pavement, and I have to lift my feet high. I'm not good at having deep conversations when I walk and that's an expression of the fact that sure I can walk and I don't really think about it, but I think about it more than others.

In another interview, LJ, a 58-year-old spastic paraplegic, gives a similar description of walking:

I can do considerably more if I walk alone and there is no one talking to me, no one saying anything, nothing that disturbs me... The expression 'walking with your head' fits nicely with the fact that, if I'm just walking and you were to say my name or something, then I'd almost fall. I'll freeze completely and won't be able to walk. I'll freeze and that fits nicely with the fact that I'm walking with my head.

NJ and LJ don't necessarily experience their body as being discomforting while they walk, but they experience it as being disabling, since it's 'at the front' of their experiences, drawing their attention towards their feet and surroundings. This phenomenon makes it difficult for them to have deep conversations with other people, but it's nonetheless something that they have attuned to and learned to live with.

This description doesn't exclude the possibility that NJ, LJ and other persons with congenital disabilities may also experience other aspects of disability. It is the entire continuum of experiential aspects, i.e. the pre-reflective, attuned and reflective aspects, that constitutes the experience of disability.

## 5. Conclusion

In this paper, I have tried to develop a phenomenological model of disability by arguing for a different methodological and conceptual framework from that used by the existing phenomenological approach. I have described the experience of disability as being gradually different from, rather than a disruption of, the experience of being able, and argued that the experience of disability is complex and dynamically influenced by both intrinsic and extrinsic factors. I've described different experiential aspects of disability—the pre-reflective, attuned and reflective aspects—demonstrating that the experience of disability comes in different degrees. Overall, I've tried to advocate the necessity of including the personal aspects and experience of persons living with disabilities in an account of disability, emphasizing notions such as 'embodiment', 'motor intentionality' and 'I can'. This phenomenological model should, therefore, be seen as a contribution to the clarification of the personal factors of disability in developing a complex, dynamic and multidimensional framework for understanding disability.

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## Chapter 5

# Predicting the Future for Motor Control in Sense of Agency: Insights from Cerebral Palsy

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# Predicting the Future for Motor Control in Sense of Agency: Insights from Cerebral Palsy

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## 1. Introduction

The influential *Comparator Model (CM)* of Sense of Agency (SoA) has recently been found in need of either improvement or rejection, because it fails to account for cases in which there is SoA, but no motor comparison between predicted and actual sensory information. There are currently two ways to go from here in the discussions of SoA. The first is to salvage and develop the CM to account for such cases, which is the task of what can be called the *Cue Integration Model (CIM)* of SoA. The basic idea in CIM is that SoA is more complex than presented in CM, and it depends on the integration of different levels of internal and external motor, cognitive, affective and contextual cues. The aim for CIM is to illustrate how the integration of these cues makes us experience SoA.

The second way is to jump ship and operate with a different understanding of motor control than seen in CM. The second and the newcomer in the discussion of SoA go by different names such as ‘Active Inference’ (Friston 2009; Adams et al. 2013), ‘Embodied Inference’ (Friston et al. 2013), ‘Embodied Prediction’ (Clark 2015), ‘Integral Forward Model’ (Pickering & Clark 2014) and ‘Action-Oriented Predictive Processing’ (Clark 2013). For the sake of clarity, let’s call this the *Active Inference Model (AIM)* of SoA. Contrary to CM, predictions in AIM encode the perceptual intention of the action and function as the motor command. Thus, the aim for AIM is to explain how predictions of the actions actually performed make us experience SoA.

How should we decide between the two models? The questions become: is a descending neural signal a motor command (CM and CIM) or a prediction (AIM)? Do predictions encode the cause (CM and CIM) or the intention (AIM) of the action? And, ultimately, does SoA occur due to cue integration (CIM) or active inference (AIM)?

To discuss the three models CM, CIM and AIM, this chapter presents studies of the motor control disorder cerebral palsy (CP). This disorder makes an interesting contribution, because it has been overlooked in the debates of SoA, and it’s a case where SoA is experienced, but where there is no motor comparison. The insight we take from discussing the case of CP is that both CIM and AIM explain SoA in Bayesian terms and provide a prospective explanation of how SoA can occur in CP: either fluent action selection becomes a statistical cue for actual motor control in CP (CIM), or prior beliefs function as a probabilistic prediction of control (AIM). CIM and AIM both operate with a notion of SoA that, in comparison to CM, is not a question of either/or, i.e., either there is motor comparison or not, but a question of more or less. SoA



can be experienced at different levels, which, in CIM, is due to the integration of different motor, cognitive, affective and contextual cues, and, in AIM, is due to more or less precise second-order predictions of first-order ones.

However, one crucial issue for CIM and AIM is that, due to their Bayesian and prospective focus, the influence of actual motor control in SoA needs to be accounted for. We discuss the issue of motor learning in relation to CP and, in doing so, question CIM since, it reduces the influence that actual motor control has for SoA. AIM provides an explanation of CP that requires further development but, as a point of departure, it avoids this problem in CIM. Based on the case of CP, we therefore propose that the promising insights for future development of the discussion of motor control in SoA are to be found in AIM.

## 2. The Comparator Model

SoA can be described in general terms as the experience that I'm the one who is causing, generating and controlling an action (Gallagher 2000). The comparator model (CM) of sensorimotor control (Wolpert et al. 1995; Wolpert & Kawato 1998; Wolpert et al. 1998a; Kawato 1999; Wolpert & Ghahramani 2000; Wolpert & Flannagan 2001; Blakemore et al. 2002) has been highly influential in describing SoA. By focusing on neurological, computational and experiential differences between voluntary and involuntary movement in normal, pathological and experimental cases, CM establishes two internal models in the motor system suggested to occur in the cerebellum, namely the inverse model and the forward model. The inverse model functions as the driver of the actions by converting intentions (desired states) into motor commands. The function of the forward model is to predict the future state of the motor system by using an efference copy of the motor command. This prediction is called the corollary discharge and makes it possible for the motor system to compare the predicted with the actual feedback and distinguish between self-produced (re-afferent) and externally produced (ex-afferent) sensory effects. If there is a match in comparison between the predictive and actual sensory information, the sensory events are recognized as self-produced, and SoA is experienced (Frith 1992, 2004, 2005; Frith et al. 2000; Gallagher 2000, 2005; Tsakiris & Haggard 2005; Haggard 2005).

### 2.1. SoA without Motor Comparison

CM has made substantial contributions to the description and explanation of SoA but, recently, Synofzik et al. (2008a) have argued that a match in comparison between predicted and actual effect signals is neither necessary nor sufficient for SoA. Synofzik et al. take different experimental studies, e.g. that of patient GL, a deafferented person (Fournier et al. 2002; Farrer et al. 2003), to show that it's possible to experience SoA despite a mismatch at the comparator, and that mere comparison between efference copy and reafference is

not sufficient for SoA. They also argue that the comparator isn't necessary for explaining SoA, because subjects typically plan, monitor or perceive their actions and corresponding effects in intentional and perceptual terms (e.g. their underlying goals) and not in motor-related terms (Mechsner et al. 2001; Mechsner 2004; Prinz, 2003; Saito et al. 2005). One might therefore in some cases focus only on such intentional and perceptual terms in explaining SoA.

Pointing to the work of Wenger and colleagues, Synofzik et al. additionally argue that we don't need to change any motor mechanism or sensory input in order to alter SoA. As Wenger and Weathley have shown, it's possible to induce 'illusory' SoA for movements that subjects haven't made, by priming them with relevant beliefs and thoughts just before the movements (Wenger & Weathley 1999). This suggests a cognitive reconstruction view of SoA, where motor control understood in CM terms is downplayed, and SoA is taken to be inferred retrospectively (Wegner 2002).

Others have also found the CM account of SoA problematic (e.g. Bayne & Pacherie 2007; Haggard & Tsakiris 2009) and, discussing Sato and Yasuda's illusions studies of SoA (Sato & Yasuda 2005), Knoblich and Sebanz (2005) argue that it's possible to experience SoA in action errors where there is no match between predictive and actual signals. They point to both a possible Wegnerian explanation of this phenomenon and to recent studies on error monitoring (Yordanova et al. 2004; van Schie et al. 2004). These studies suggest that, in erroneous actions, internal monitoring mechanisms do not, as suggested by CM, signal the error based on comparison but, rather, on the detection of a conflict that occurred while choosing between several action alternatives. SoA could therefore be experienced in unintentional actions, because an error-monitoring signal is used to readjust the system, 1) serving as a direct indication of agency, or 2) influencing post-hoc evaluations of the performed actions.

Taken together, these studies suggest that CM fails to account for certain cases in which there is SoA, but no motor comparison between predicted and actual sensory information.

### **3. The Case of Cerebral palsy**

The strength of the traditional CM model of SoA, and its further development in CIM, has primarily been the way in which it addresses and accounts for many different disorders of SoA, typically cases such as schizophrenia (Frith 1992, Daprati et al. 1997; Franck et al. 2001; Fletcher & Frith 2009), brain damage to the parietal cortex (Sirigu et al. 1999; Sirigu et al. 2004) and anarchic hand syndrome (Della Sala et al. 1991). Recently, AIM has provided explanations for many of the same disorders within its framework (Adams et al. 2013; Edwards et al. 2012; Brown et al. 2013; Bayne & Hohwy 2014; Hohwy in press).

However, discussion of the motor control disorder cerebral palsy (CP) has been more or less overlooked. It would, nonetheless, make an interesting contribution to the debate, since the current impasse concerns our

understanding of motor control and its relation to predictions, and cases are highlighted where there is SoA, but no motor comparison. These issues are precisely what is at stake in CP.

### 3.1. Spasticity in CP

As an umbrella term, cerebral palsy (CP) is defined as a group of disorders affecting the development of postural and motor control, occurring as a result of a non-progressive lesion in the developing central nervous system (Bax et al. 2005). In 90 % of the cases, the lesion occurs during pregnancy (Ellenberg & Nelson 2013), making CP the most common type of disorder associated with lifelong motor impairment (Aisen et al. 2011). At the same time, CP is a heterogeneous condition that varies according to the particular brain lesion and individual in question. As a result, CP is typically classified according to its different types of motor symptoms (spastic, dyskinetic, or ataxic) and to the bodily location of the motor impairment (mono-, hemi-, para-, and tetraplegia). Spasticity is seen in most cases of CP, where the lesion affects the upper motor neurons, damaging the motor neurons' ability to regulate descending motor pathways, which results in muscular overactivity (e.g. exaggerated tendon reflexes and hypertonia) (Dietz & Sinkjaer 2007; Sheean & McGuire 2009).

Recent research suggests that, depending on the location, extent, and temporal development of the lesion, CP additionally includes deficits in proprioception (Lee et al. 1990; Riquelme & Montoya 2010), perceptuo-motor functioning (van der Weel et al. 1996), cross-modal mapping of vision and proprioception (Wann 1991), spatial tactile discrimination (Sanger & Kukke 2007), and joint-position sense and kinesthesia (Wingert et al. 2009). Thus, both the efferent and afferent signals and the processing of these signals seem to be disturbed in CP, and spasticity can generally be seen as one characteristic feature of this disturbance.

We are going to discuss spastic CP in this paper, and a recent definition of spasticity defines it in terms of involuntary movements as “[d]isordered sensory-motor control, resulting from an upper motor neuron lesion, presenting as intermittent or sustained involuntary activation of muscles” (Pandyan et al. 2005, 5). The main question we are going to pursue is, therefore, *what is the experience of SoA like, while living with involuntary movements?* We will look at three studies that have dealt with these issues in children and adults with spastic CP.

### 3.2. Judging SoA in Children with CP

Following the principles of the so-called alien hand-experiment (Nielsen 1963), two recent studies (Ritterband-Rosenbaum et al. 2011 and 2012) have investigated the ability of children with CP to judge whether movement of a virtual moving object is caused by themselves or an external source. The first study was designed as a cross sectional experiment including children diagnosed with spastic hemiplegia CP (n: 24) and a control group consisting of healthy children (n: 65) and healthy adults (n: 16). These three groups

had to produce straight drawing movements on a pen tablet, which was not visible to the subjects. The produced movement was presented as a virtual moving object on a computer screen, and the participants were asked to judge after each trial whether the movement of the object they saw on the computer screen was generated by themselves or by a computer program, which randomly manipulated the visual feedback by angling the trajectories 0, 5, 10, 15, 20 degrees away from target.

The results of the study show that, compared to the healthy groups, the children with CP took longer to complete the movement and that a greater curvature in the actual produced movement produced a longer trajectory. Also, when the trajectory deviated by more than 10 degrees, the children with CP were less likely than the healthy adults and children to report that the computer was responsible for the movement of the object. As a consequence, the children with CP more frequently attributed the computer's movements to themselves, and attempted to counteract the movement of the object, which resulted in larger discrepancy between their own movement and the computer-generated movement of the object.

The study therefore suggests that, in contrast to healthy adults and, to some extent, healthy children, children with CP don't use well-learned predictive (feed-forward) motor mechanisms. Their slow, unsteady movements suggest that they were forced to use a feedback strategy in which the movement had to be corrected repeatedly based on the available visual feedback (Milner 1992, Desmurget & Graton 2000, Gritsenko et al. 2009). The study proposes that this strategy arises because of their intention of movement is poorly integrated with visual and proprioceptive information about the performed movement. This integration is defined, using the CM framework, as SoA and, overall, the conclusion is that an altered SoA may be an important functional problem in children with CP.

In order to further understand the altered SoA in children with CP, the second study aimed to evaluate whether 20 weeks of motor, perceptual and cognitive training enhances the ability of children with CP to judge their agency in the alien-hand experiment as described in the first study. 40 children with CP were divided into a training group (n: 20) and a control group (n: 20). The training group trained 30 min. each day for 20 weeks using the internet-based home training system 'Move It to Improve It' (MiTii) (Bilde et al. 2011), which is designed to strengthen sensory-motor interaction. In contrast, the CP control group continued their regular daily activities. The ability of the children to judge their agency in the alien-hand experiment was tested before and after the 20-week period.

The results show that the training group had improved their ability to judge their agency in contrast to the control group. This was "reflected behaviorally as a reduced compensatory reaction when the computer introduced a deviation of the observed object" (Ritterband-Rosenbaum et al. 2012, 1232) and in accordance with this, "the training group was also less fooled by computer-induced movements given by a decreased curvature which indicated a compensatory motor strategy when drawing the line to hit the target following the training than the control group" (Ritterband-Rosenbaum et al. 2012, 1227). Overall, this suggests that

SoA was altered for the training group, which, according to the study, means that the children's intention of movement was better integrated with the visual and proprioceptive information about the performed movement.

From these two studies, it seems that, despite functional problems with predictive motor mechanism, SoA in CP is something that we can train and become better at judging. The study suggests that this is due to better integrating the intention of movement with external feedback, but the question is whether this actually happens due to improvements in the children's predictive motor mechanism or in their feedback mechanism, due to an improvement in the ability to judge SoA. Or, is it a combination of all such aspects? In order to further investigate these questions, we set up a study of SoA in adults with CP.

### 3.3. SoA in Adults with CP: Involuntary and Uncertain Movements

Only a modest number of studies have previously investigated the first-person experiences of living with CP (e.g. Sandström 2007; Peckitt et al. 2013), but in Martiny (2015; under review)<sup>35</sup>, the results of phenomenological interviews with adults with CP are presented. The interviews were done over a period of one year and took place at the Helene Elsass Center (HEC), a Danish habilitation center working primarily with CP. 14 participants (7 women, 7 men, age 23-57) were selected for the interviews by focusing on spastic CP. The 14 participants represented the diversity of spastic CP to a great extent, since the group included participants with a diverse range in the nature and degree of severity of bodily impairment. In relation to the gross motor function classification system (GMFCS) developed for children with CP, the participants in the study correlated to Level I-IV (Palisano et al. 1997). For a full account of the interview design and methodological considerations see Høffding and Martiny (forthcoming).<sup>36</sup>

When asked generally about how he experiences his body in performing actions, MS, a 26-year-old man with spastic hemiplegia in his left side, describes it as follows:

“I experience a bit of tension, which makes it difficult for me to perform the actions that I want to do. So it makes it a bit involuntary, you can say... It doesn't have to be that much, but it can just be a small degree, which brings about the actual effect that I become uncertain and therefore ask for a helping hand.”

MS describes the movements as being involuntary, since they complicate the performance of the action he intends to do, which then creates an uncertainty in his actions. This performance difficulty and uncertainty of the action is described by all 14 participants through descriptions such as: they experience ‘a resistance in their movements’, they ‘have stiffness in their movements’, their ‘body is weighing them down’ or their ‘body is working against them’. The participants describe different aspects of involuntary movements and

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<sup>35</sup> See chapter 4 and 6 in this Ph.D. dissertation.

<sup>36</sup> See chapter 3 in this Ph.D. dissertation.

uncertainty, but common to their descriptions is that they complicate performing daily actions, such as keeping balance while walking or exercising fine motor control over the movements of their fingers while making dinner or putting on clothes.

HJ, a 48-year-old spastic paraplegic, exemplifies the uncertain nature of his movements in the case of walking:

“There is always an element of something like uncertainty or whatever you would call it. There is always an element of constant adjustment. It’s difficult to explain. Call it reaction, which is that I have to react against my own body. It’s like the difference between if you walk normally and if you walk with weights on your feet. I just don’t have anything to compare it to, since I haven’t had the weights off my feet. I can just see that everything is more difficult for me than for everyone else... Typical daily tasks just take more time, either because I have to do it in a different way than you do or because I become tired more easily than you.”

The experience of uncertainty arises for HJ, since he is never completely certain whether or not he will be able to perform his intended actions, and he has to constantly adjust his movements in order to do so.

Although involuntary movements and the experience of uncertainty influence their action performance, the participants nevertheless describe that this is not something that they are typically aware of in their daily lives. TV, a 28-year-old man and spastic paraplegic, says while addressing the interviewer:

“you would probably be better at noticing [the involuntary movements], because I don’t experience them, and that has something to do with the fact that it has always been like that for me... It’s like people that have tinnitus, I guess, since if they have had it for a long enough period of time, then it’s possible to have the ringing noise, without them reflecting upon it. So, it has to do with your preconditions.”

CP is congenital, which means that the participants have developed their agentive abilities according to their motor control disorder and have learned to perform many of their daily actions despite their involuntary movements. This is typically done in their own homes and, for many of them, involves the use external tools such as crutches. As MP, a 31-year-old woman with spastic paraplegia, says: “I don’t think that I’ve thought that much about something being different. It probably has something to do with the fact that when you have learned something, then that’s the way you are going to do it.” MS gives a similar description when asked to describe his experience of motor control in tying his shoes:

“[My movements] are also not something I notice. Again, I’ll say that if you look back in time, then that’s the kind of thing I’ve trained a lot in both occupational therapy and things like that. Precisely in order to be able to [tie my shoes], to do actions like that. But now it’s not something I think about, because I can do it and I uphold it by putting on a shirt and stuff like that. Now it has just become automatic, but I know that an enormous amount of practice is necessary for being able to perform fine motor control things. For the same reason, I’m not good at drawing, because I don’t have that much control of my hand.”

Thus, despite their motor control issues, it's still possible for the participants to complete their actions, but the way in which they perform them requires different motor strategies. For completing actions successfully, practice and learning is necessary, as it is for any person. Nevertheless, there is a fragile relation between practice and action in CP, as hinted in MS's description above. FN, a 39-year-old spastic tetraplegic, describes her experience of riding her bike to work:

“[i]t's something like being a child and having to learn something new. I do experience that my body and my brain have tried the movements before, and it would of course take a lot longer if I hadn't biked before, but basically the feeling I have in my body is like starting from the very beginning again... You don't have to think when you take a step or use your arm or something, whereas I can feel that I need to use more thought capacity... This contributes to the experience that I'm tired in my head, probably because I use extra energy in doing normal and daily things, which you don't have to think about in the same way.”

Despite knowing how to bike, the constant occurrence of spasticity makes it difficult for FN to complete her action. FN has to therefore use an enormous amount of cognitive energy in order to be able to bike and accomplish her daily activities.

In CP, there is a fine line between acting without thought, acting automatically, as MS puts it, and acting with thought, a phenomenon FN describes in the above example of biking. Depending on the situation, they are able to do both but, in many cases, they use cognitive strategies to control their movements. JN gives the following example of how he walks:

“It's not because we [people with CP] think about everything, but we just use more energy and strength to think about, for example, not falling or looking at where I'm [sic] going. I'm not good at compensating when I walk, because I use extra strength not to fall between the bike lane and the pavement, and I have to lift my feet high. I'm not good at having deep conversations when I walk and that's an expression for the fact that sure I can walk and I don't really think about it, but I think about it more than others.”

According to JN, this means that:

“I have gotten used to my body being uncertain, so, by contrast, I would say that I experience being in full control of both my body and thoughts in the way that I have become more aware of how my body works. It may sound strange, but if you don't get fixed on all the uncertainties and mistakes I make, it actually means that I've used so much time and effort to refine these complications... I actually know my arsenal of complication.”

MS says that his way of controlling his actions is gradually related to the way he believes people normally act:

“My body does what I want it to do and I know the actions that are difficult. I can act before they happen, before it becomes a problem. But it’s a question of degree...I have to correct my movements, when something unexpected happens, but everybody has to do that. I just have to do it to a much larger degree.”

As a result, HJ wouldn’t use a term like ‘uncertainty’ to describe his own bodily experiences:

“I don’t have anything [to] compare [my body] to. If we need to say something is uncertain, we need to know what is certain, and I don’t know that, because I haven’t had any other bodies than this one. So I don’t have anything to compare it to and so I won’t call it uncertain, because I have the parameters I have. But if I look at other people and I look at what I can and they can, I see there is a difference. In this way it’s uncertain. But my own personal experience of my body is like it is.”

What these first-person descriptions of adults with CP suggest is that, despite living with involuntary movements, they have developed according to their disorder, and they experience SoA in their movements, where no thought is needed in order to accomplish the action and where no uncertainty arises. When reflecting, they are aware of the difference between the way they experience controlling their movements and the way others seem to do so. The interesting question is how it’s possible to experience SoA in the case of involuntary movements?

### 3.4 Understanding SoA in CP: Problems with CM

As mentioned, both efferent and afferent signals and the processing of these signals seem to be disturbed in CP. This disturbance is seen in the study of children with CP, since they don’t use predictive motor mechanisms and, when focusing on their judgment of SoA, they have an alternate integration of intention and sensory information. This can, however, be trained, which is supported by the first-person descriptions of adults with CP. It seems that, although involuntary movements are a part of their adult life, it’s nevertheless possible to experience SoA in their daily movements. How should we understand these aspects of CP in relation to the current discussions of SoA?

Interpreting CP within the traditional CM framework makes it difficult to understand why persons with CP would experience SoA at all. One cornerstone of CM’s account of SoA has always been the fact that there is no SoA in involuntary movements, a point that has been used to distinguish SoA from *Sense of Ownership* (SoO), i.e., the experience that ‘my body is moving regardless of whether the movement is voluntary or involuntary’ (Gallagher 2000). In involuntary movements, no motor command is issued, no efference copy is made of the command and, therefore, no comparison, or, ultimately SoA experience, is possible. This doesn’t seem to be the case in CP, since they seem to experience SoA even though efferent and afferent signals are wrongly processed.



The studies show that children with CP are bad at making judgments about SoA, and the first-person descriptions highlight that the SoA that adults with CP experience isn't always a post-hoc reflective inference or evaluation of their own movements. They are typically not aware of their involuntary movements. How can wrongly-issued motor commands, disturbed predictive motor mechanisms and deficits in reafferent feedback still lead to SoA, especially if the judgment of SoA is either disturbed or not directly involved?

The second study of children with CP suggests that training sensory-motor interaction improves how the sensorimotor system processes efferent and afferent signals, which could explain why they become better in judging their SoA. However, even though the training makes the children better at judging SoA by adjusting the comparison mechanism, it does not correct the disturbances in their motor system. Spasticity is still a large part of their daily lives, as indicated by the first-person descriptions of the adults with CP.

In the rest of the paper, we will try to give an explanation of CP through the lens of CIM and AIM, with the ultimate purpose being to discuss their respective notions of 'motor control' in the context of CP.

## **4. Cue Integration Model of SoA in CP**

In CM, the comparator mechanisms do the heavy lifting of explaining SoA. One mechanism compares desired and predicted states and evokes a feed-forward and predictive type of control that enables the motor system to deal with uncertain information, such as noise and delays (Franklin & Wolpert 2011). This feed-forward comparison makes us experience a sense of being in control despite such uncertain information (Frith 2005). Another comparison mechanism, which compares predicted states and estimated actual states, makes it, as already mentioned, possible to recognize sensory events as self-produced and to, thereby, experience SoA.

However, cognitive processes such as deliberation, planning, and intention formation are typically presupposed in CM, and affective influences such as motivation, valence, appraisal, anxiety, trust, and confidence are overlooked when it comes to the specific influence they have on motor processes. CIM supplies CM with such cognitive, affective and other contextual cues and illustrates how they, together with motor cues, deal with uncertain information in order to make us experience SoA. Thus, it might be the additional cues that make it possible to bypass the motor control issues in CP and allow people with CP to experience SoA nonetheless.

### **4.1. Different Cues and Their Optimal Integration**

The basic idea in CIM is that SoA is complex and depends on the relation of different lower and higher levels of internal and external cues (Bayne & Pacherie 2007; Gallagher 2007, 2012, 2013; Synofzik et al.

2008a, 2008b, 2009, 2013; Haggard & Tsakiris 2009; Fletcher & Frith 2009; Knoblich & Reep 2009; Moore et al. 2009; Moore & Fletcher 2012; Chambon et al. 2014). In order to clarify this idea, the model appeals to the cues' difference in strength and weight and to a distinction between two levels of SoA: *feelings of agency*, pre-reflective, non-conceptual and 'thin' experiences closely related to motor control, and *judgments of agency*, more complex and reflective attributions and inferences of agency. This should not be understood as a sharp distinction, since the point of making the distinction is to clarify how different cues modulate different levels of SoA.

Internal motor cues are the action selection processes, motor output signals, and multisensory predictions that are processed by the forward modeling and that include lower-level sensorimotor predictions and higher-level perceptual predictions (Gallagher 2007; Jeannerod 2009; Knoblich & Repp 2009; Pacherie 2008, 2010). The lower level predictions may occur in the muscle spindles, since the afferents are able to predict 150 ms into the future (Dimitriou & Edin, 2010), and the higher level in the posterior parietal cortex (Desmurget et al. 2001; Shadmehr & Krakauer 2008; Wolpert et al. 1998b).

The internal multisensory and motor cues are related to higher levels of internal cognitive cues, such as prior knowledge, planning, deliberation, beliefs and the formation of intentions formation. Depending on the context, these cognitive cues may influence the lower-level cues to a greater or lesser extent. Whereas the context provides external cues such as sensory input, both external and internal cognitive and motor cues may generally be influenced and weighted by affective cues such as motivation, valence, appraisal, and the feeling of personal abilities. These affective cues have been largely neglected in the debates on SoA but, recently, Synofzik and colleagues have argued for an *affective coding of agency*, where emotional cues may shape agency in three different ways: they may 1) shape it prospectively, 2) shape the immediate feeling of agency and 3) shape the post-hoc judgment of agency (Gentsch & Synofzik 2014, see also Synofzik et al. 2013).

One suggestion as to how all these different internal, external, motor, cognitive and affective cues are integrated is the so-called *optimal cue integration* proposal (Fletcher & Frith 2009, Synofzik et al. 2009, 2013; Moore & Fletcher 2012). This integration is understood in a Bayesian framework, which means that the cues are taken to operate as predictions in different hierarchies and modalities and according to different degrees of reliability. The cognitive and affective cues provide the so-called priors for the lower-level multisensory and motor cues. This means that the higher levels predict the interpretation of the lower ones by attaching different weight to the lower-level cues. The weight and influence of the higher-level predictions is based on the reliability of the predictions, which relates both to the strength of the priors and to the contextual external cues.

The different hierarchical predictions help to reduce the degree of uncertainty pertaining to the motor control system by integrating the different levels of external and internal cues. Bayesian cue integration is

therefore a product of the strength of the priors and the weight of the predictions, and their integration reduces the degree of uncertainty in the motor system by creating a reliable and optimal strategy for predictive control (Franklin & Wolpert 2011; Moore & Fletcher 2012). Thus, in CIM, SoA is described as an experience that is based on this reliable and optimal strategy of integrating cues.

A number of studies have shown how cues can be integrated in different ways so as to allow for different experiences of SoA. Using an intentional binding paradigm, Moore and Haggard (2008) have shown that, if motor predictions are strong, even in the absence of an action outcome, the prediction itself is sufficient to produce binding. If the motor prediction is weak, binding will only occur if the outcome is present. Moore et al. (2009) illustrate that both priming and motor signals influence SoA. The influence of both cues is interactive and determined by their reliability. Other studies reveal a modulation in temporal binding when affective cues such as monetary gains and losses (Takahata et al. 2012) or negative emotional vocalizations (Yoshie & Haggard 2013) are introduced. Studies have also shown that cognitive cues such as prior authorship beliefs will modulate sensory attenuation and intention binding (Desantis et al. 2011, 2012).

## 4.2. A Prospective Explanation of CP?

Studies of children with CP show that they are bad at making judgments about SoA, and the first-person descriptions highlight that the SoA that adults with CP experience is not always a post-hoc reflective inference or evaluation of their own movements. Thus, to describe these aspects in retrospective and reflective terms isn't promising. However, the development of Bayesian cue integration in CM provides CIM with an important aspect of prospective agency (Gallagher 2012, 2013; Chambon & Haggard 2013; Chambon et al. 2014; Gentsch & Synofzik 2014). As seen above, cognitive and affective cues influence internal motor cues, which makes it possible to experience SoA even without reafferent cues or any match in comparison.

One way to explain this prospective agency in relation to motor control is by focusing on action selection (Chambon & Haggard 2013). Action selection in CM highlights the functional role of the inverse model and its ability to generate an intention and convert it into a motor command. This generation and type of intention operates mainly below the threshold of consciousness and refers to the neural preparation of the action, i.e., the readiness potential (RP). A wide pre-frontal-parietal network, including the posterior parietal cortex (PPC), the anterior cingulate cortex, the supplementary motor area (SMA), and the dorsolateral prefrontal cortex (DLPFC), is said to be responsible for bringing the motor intention into awareness (Haggard & Magno 1999, Haggard 2005; Desmurget & Sirigu 2009). When the SMA releases the motor command by suppressing the inhibitory mechanism on the primary motor cortex (M1) (Ball et al. 1999), the experience of being about to move, a *sense of urge*, occurs. This experience is said to have a motoric, egocentric and internal component (Haggard 2005).

The experience of intentions, nevertheless, contains a second component that refers to the goal object or event and has sensory rather than motor content (Haggard 2005). This component is a *sense of the effect*, which uses an external reference frame that focuses on the goal or target location, and which seems to include parietal processing.

Recent studies (Wenke et al. 2010; Chambon & Haggard 2013; Chambon et al. 2014) have used subliminal priming cues to influence the inverse model by reducing conflicts between alternative action programs (Flemming et al. 2009). This makes the action selection process more fluent and uncontested, and it shows how external cues modulate SoA by influencing the sense of effect. In these subliminal priming experiments, the fluency of action selection is achieved before the action itself and isn't retrospectively based on judgments of primes and effects alone, since, in contrast to other prime studies (e.g. Wegner & Wheatley 1999), the participants didn't consciously perceive the primes. Also, the priming didn't influence the actual control the participants had over the outcome of their actions, since the action outcome was the same in both priming and non-priming cases. Nevertheless, the fluency of action selection strongly influences the participants' SoA, which suggests that it's possible to experience SoA prospectively and independently of actual motor control and reafferent cues.

This could mean that the children with CP have in their training process changed their control strategies to rely on the cue of selection fluency. It has been shown that errors in task performances lead to a feeling of dysfluency, i.e., the feeling that something is wrong, without leading to specific knowledge as to what is wrong (Arango-Muñoz 2010; Wenke et al. 2010; Charles et al. 2013). This 'epistemic feeling' of there being something wrong in the control of the action is sufficient to modulate the later judgment of control and SoA. Thus, it could be that the children with CP become better at relying on this implicit feeling of selection fluency in making their judgment about SoA.

This interpretation would also make sense in relation to the case of adults with CP. Wenke et al. (2010) describe the feeling of action 'fluency' as 'effortless.' The feeling of effort in controlling one's actions is seen in the literature as an increased demand in cognitive control (McGuire & Botvinick 2010). By contrast, action fluency can be described as experientially smooth and effortless cognitive processing (Oppenheimer 2008), a description that fits with those of the adults with CP, who describe that, when they have learned to perform an action, they still experience a pre-reflective feeling of SoA despite their involuntary movements.

This explanation of prospective agency in action selection seems to take actual motor control out of the equation of SoA. Nevertheless, an action effect should not be a matter of mere chance but should rather be reached via means of control that are consistent with the agent's intention (Pacherie 2008; Pacherie & Dokic 2006; Chambon & Haggard 2013). The prospective aspect of SoA should therefore be understood as a convenient proxy for motor control, because fluent action selection becomes a cue for actual control (Chambon & Haggard 2013; Chambon et al. 2014). This means that prospective agency reflects learned

experiential metacognition, thereby indicating that, if action selection is fluent, we experience the intended effect as likely to be fulfilled. It's therefore learned experiential metacognition that in the end explains SoA in the case of CP, because actual motor control is downplayed as a cue, and the prospective fluent selection cue is emphasized as a predictor of actual statistical control over the external environment (Chambon et al. 2014).

This proposal for understanding SoA is at the same time interesting and problematic, since the explanation given by CIM, which illustrates Bayesian and prospective aspects of SoA, is suddenly very close to the way in which AIM understands SoA.

## 5. Active Inference Model of SoA in CP

At the outset, both CM (Chambon & Haggard 2013) and AIM (Brown et al. 2011; Pickering & Clark 2015) can be described as formalized versions of an ideomotor account of motor control (Lotze 1852; James 1890). This ideomotor account proposes that the intention (the idea) to act is sufficient to drive the action, so there is no need to operate with additional and intermediate mechanisms, such as the selection fluency described in CIM above. Nevertheless, AIM operates with a very different understanding of motor control than CM, and one crucial difference is their definition of predictions.

### 5.1. Predictions Drive Actions

As illustrated above, in CM, predictions encode the cause of actions, which is done through an efference copy of the motor command. In AIM, however, predictions encode the perceptual and sensory consequences of actions, which comprise the intention to act (Adams et al. 2013). This means that predictions function as descending signals and that they are in and of themselves sufficient to drive motor signals and enable actions to occur. Thus, in contrast to CM, the perceptual and motor systems go hand in hand in AIM, and the striate (visual) cortex should be taken as being just as much of a motor cortical area as is the primary motor cortex (Friston et al. 2010, 2011; Adams et al. 2013).

Predictions drive actions by means of their comparison with muscle spindle afferent (Ia and Ib) signals at the spinal level, creating what is called a proprioceptive prediction error. The purpose of the nervous system is to minimize the prediction error between predicted and actual signals (cf. the free energy principle).<sup>37</sup> In computational literature, this kind of minimization is known as predictive coding, and it occurs hierarchically at different cortical levels by changing the activity in neuronal populations encoding predictions and prediction errors (Rao & Ballard 1999).

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<sup>37</sup> We will not go into further detail about the free energy principle here. For an in-depth explanation, see Friston (2013), Friston et al. (2010) and Feldman & Friston (2010).

In the context of AIM, this predictive coding can be done in two ways: either by changing the predictions to better cohere with the proprioceptive input, a perceptual process that changes synaptic activity and connection strengths, or by changing the proprioceptive input to conform to the predictions, a process that corresponds to the performance of an action. Although the first process is related to the perceptual system and the second to the motor system, both processes should be understood together as one single active inference mechanism (Brown et al. 2011; Adams et al. 2013).

Thus, in AIM, there is no need to operate with two distinct internal models for motor control, one driving action and another predicting action. There is also no need to operate with an efference copy of the motor command (Friston 2011; Adams et al. 2013; Pickering & Clark 2014; Clark 2015). Active inference proposes an integral generative model, where descending predictions function as both the forward model, predicting sensory consequences (i.e. the corollary discharge), and the inverse model. The predictions cause the movements by functioning as the motor command in the minimization of prediction error. The motor command in this model encodes at the spinal level both the intention of the movement and the context-sensitivity of the limb position. The actual movement is then executed by the classical reflex arc, since the descending predictions act on both alpha and gamma motor neurons in order to cancel out proprioceptive prediction error (Friston et al. 2010).

This being the case, the explanation given by AIM omits the contribution of the cerebellum to the forward model (Adams et al. 2013), and proposes that predictions regarding the sensory consequences of intended movement arise at a high hierarchical level, for example, in the pre-supplementary motor area (pSMA) (Edwards et al. 2012). In contrast to CIM, the awareness of the motor intention is therefore a perceptual sense of effect, rather than a motoric sense of urge to move. In other words, movements are specified “in terms of what we want to see, as opposed to what we want to do...” (Friston et al. 2010, 240. See also Edwards et al. 2012).

## **5.2. Abnormal Precision and Uncertainty in CP**

The symptoms of CP, such as paralysis, spasticity, weakness, dystonia and tremor, have within the AIM framework been discussed as falling under what are called Functional Motor and Sensory Symptoms (FMSS) (Edwards et al. 2012). The overall idea is to explain these symptoms as abnormal precisions or uncertain predictions. A computational explanation of spastic CP within the AIM framework is that “proprioceptive prediction errors retain a high precision but are not properly informed by descending predictions – leading to spastic paralysis” (Adams et al. 2013, 236). To explain these abnormal precisions of prediction error, AIM reads the active inferential process through Bayesian lens.

The AIM model is Bayesian because, at any hierarchical level, the outcome of active inference, i.e., the posterior beliefs about perceptual input, is based on prior beliefs about the world and on current sensory

information. This is called empirical Bayes, since the brain doesn't generate all of its prior beliefs *de novo*, but estimates them from current sensory information. Prior beliefs are conveyed by top-down predictive connections between different hierarchical levels, whereas sensory information is evidenced bottom-up through the hierarchy as prediction errors until it is minimized perceptually or actively (Adams et al. 2013).

In predictive coding, prior beliefs and sensory information are encoded as probability distributions, which means they have a mean value (expectation) and a precision (inverse variance). It's the precision of prior beliefs and sensory information that is interesting in the context of SoA, since it determines the weight that such beliefs and information are given in active inference. In other words, by determining the relation between prior beliefs and sensory information, the precisions determine the weight of prediction error and whether or not we should act (Edwards et al. 2012). As described by Pickering and Clark, when "proprioceptive prediction error is highly weighted yet suitably resolved by action, we move, and we may feel a sense of agency or ownership regarding those actions" (Pickering & Clark 2014, 4).

The precision of prediction error is described as a second-order prediction, which occurs at a higher level than the first-order proprioceptive prediction of afferents and sensory input (Brown et al. 2011). In predictive coding, the precision of prediction errors is encoded by the synaptic gain of the cells that encode them, namely, the superficial pyramidal cells in the upper layers of the cortex (Mumford 1992). This means that, in AIM, second-order predictions are of the precisions of sensory input and optimize the post-synaptic gain of prediction error (Brown et al. 2011; Adams et al. 2013). The precision process should therefore be understood as analogous to the statistical method of weighting the first-order mean sensory input according to the prior beliefs of its standard errors. The gain or postsynaptic responsiveness can be altered and optimized by means of several factors such as neuromodulators of NMDA, acetylcholine and dopamine receptor activation (Feldman & Friston 2010; Brown et al. 2011).

It's the abnormality of the second-order prediction of precision that, according to AIM, is at issue in CP. Pathologically high precision is given to intermediate predictions of movements, relative to higher (intentional) levels of the hierarchy. This means that, even though the prediction error isn't being properly informed by descending predictions, it's wrongly taken as a precise and highly weighted motor command. Thus, the motor system induces autonomous activity (attractor dynamics or central pattern generators) generating somatosensory and proprioceptive predictions that elicit a movement by classical reflex arcs. At the same time, the over-precise and overweighed prediction errors are passed forward to higher levels as movements not predicted by the higher hierarchical levels. This presumably causes the movements to be interpreted as involuntary and uncertain (Edwards et al. 2012).

This explanation fits with the descriptions above, namely that adults with CP experience not being able to perform their actions exactly the way they intend to, i.e., their motor predictions are wrongly processed. Since the motor predictions still cause the movements, the movements are experienced and described as

involuntary. Perceptual processes might then try to change the predictions to better cohere with the proprioceptive input, only to wrongly issue new motor predictions. This would create a dynamical feedback loop that requires larger corrections of the movements in CP than in normal cases. This is precisely what the studies of children with CP and the adults' descriptions both suggest.

Nevertheless, in the context of AIM, SoA is an active inference issue and is therefore defined in terms of prior beliefs. In fact, AIM distinguishes between *actions* as states of the world and prior beliefs about future actions, which are understood as *control* states. It's the control states that constitute SoA in AIM, which means that SoA becomes a probabilistic prediction of control over actions actual performed (Friston et al. 2013). The prediction of control depends on the precision of prior beliefs, which, in the cortex, is related to a top-down optimization process called attention (Feldman & Friston 2010). AIM defines the notion of 'attention' as the weighting of prediction error in relation to prior beliefs and action preparation, which means that attention should be understood as an increase in the gain of proprioceptive channels during motor preparation.

Thus, the way in which AIM can interpret what happens in the study where children with CP become better at judging SoA, and in the descriptions of adults with CP who do not experience their movements as involuntary and uncertain, is in terms of the attentional optimization of precisions. The precision of prior beliefs is optimized so as to better predict the control of their actions and, therefore, they experience, and become better at judging, SoA. The interesting question is how this happens, which leads us to the last issue of this paper, namely motor learning.

## 6. The Future of SoA and the Role of Motor Control?

We have now presented the way in which CIM and AIM respectively account for studies of CP. Interestingly, they both describe SoA in Bayesian terms, and give a prospective explanation of how SoA can occur in CP despite involuntary movements: either fluent action selection becomes a statistical cue for actual motor control in CP (CIM), or prior beliefs function as a probabilistic prediction of control (AIM). Another interesting aspect is that, in contrast to CM, where SoA is a question of either/or, i.e., either there is motor comparison or not, in both CIM and AIM, SoA becomes a question of more or less. SoA can be experienced at different levels, which, in CIM, is due to the integration of different cues, and, in AIM, is due to more or less precise second-order predictions of first-order ones.

However, one crucial issue for both CIM and AIM is that, due to their Bayesian and prospective focus, the influence of actual motor control in SoA needs to be accounted for. How does motor control relate to the intention to perform an action and to predictions, i.e. prior beliefs?



## 6.1. Motor Learning: Prior Beliefs and Intentions

In CM, motor control was originally discussed in relation to problems of motor learning. Extensive work on the matter has been done, suggesting that, in sensorimotor control, an internal model of the external world is learned (Kawato 1999; Wolpert & Kawato 1998; Wolpert et al. 2001). The notion ‘internal’ refers to processes ‘in the head,’ which means they are mental processes – desires, beliefs, deliberations, plans, judgments, intention formations – and/or brain processes – motor (efferent or afferent) signals and comparison mechanisms. When the capacity to initiate actions (generate and select actions) based on such internal processes is learned, the actions can be described as voluntary actions (Haggard 2005, Haggard and Lau 2013). Actions that merely respond to immediate ‘external’ stimuli are described as automatic, routine, impulsive, or merely reflexive (Haggard 2005).

In expanding upon the framework of CM, CIM adopts this understanding of motor control and motor learning, but in renewed Bayesian terms. Thus, the learned internal model of the external world is described in terms of prior beliefs. However, at this point, CIM and AIM start to diverge, since they have different understandings of what is meant by the notion of ‘prior beliefs’. Edwards et al. stress that, in their AIM account, they use the terms ‘prior beliefs’, ‘expectations’ and ‘predictions’ interchangeably, and that ‘beliefs’ in this sense aren’t necessarily ‘beliefs’ in the sense that philosophers might use the term, i.e., consciously held and reportable propositions. For Edwards et al., ‘beliefs’ are probabilistic and neuronally encoded representations in a hierarchical Bayesian network, and they contribute to inferring the causes of incoming sense, regardless of whether or not one is conscious of their content (Edwards et al. 2012, 3498).

CIM would probably agree with such a definition of ‘beliefs’, and explain how they are brain processes, but this means that, in accounting for SoA in CP by recourse to learned experiential metacognition, the prospective influence cannot refer to a mental or conscious level. Prior beliefs cannot influence SoA at the action selection level when converting a desire into a motor command, since the predictions encode the motor command. One way of using prior beliefs to account for SoA in CP is therefore to situate such beliefs in the context of learning *unexpected uncertainty* (Chambon et al. 2014, see also Yu and Dayan 2005), a process whereby SoA is maintained in the face of unexpected outcomes. People with CP might be able to learn their uncertain relation to the world, account for it predictively and neuronally in their prior beliefs, and then experience SoA. In situations with unexpected outcomes, as Chambon et al. 2014 point out, “agency may be retained depending on information from other available cues, namely internal signals related to action selection” (Chambon et al. 2014, 7).

The issue of action selection seems to work both for and against CIM. On the one hand, as mentioned above, it’s the internal processes that, in CM, account for motor learning. Relying on external stimulation would make the movements automatic, routine, impulsive, or merely reflexive. On the other hand, it seems

that the influence of actual motor control is slowly reduced, since, in the case of CP, it's other cues such as the metacognitive influence in the action selection that account for the SoA. Overall, in CIM, it is not motor control that does the hard work of reclaiming the CM model but, rather, the other cognitive, affective and contextual cues introduced. Based on such cues, the predictions become a filter that enables one to experience SoA despite there being no motor comparison, as is the case, for example, in CP. What then is the future of motor control in an account for SoA?

Another way to explain the learning process in CP is by reference to AIM, which, in comparison to CM and CIM, doesn't invoke any desired consequences. Active inference, as Friston et al. point out, "rests only on experience-dependent learning and inference: Experience induces prior expectations, which guide perceptual inference and action" (Friston 2011, 157). It's through learned perceptual experiences of the world that prior beliefs encode the intention of the action and that the prediction error is then able to cause the action to happen. AIM has a different understanding of what is meant by 'external stimuli' than does CIM and, since predictions are essentially a replacement for sensory signals, external stimuli can be understood as driving voluntary actions. This is the fundamental premise in an ideomotor account of motor control, where the intention is both perceptual and motoric. For Friston, this means that, instead of talking about learning internal models of the world, we need to acknowledge that an "agent does not *have* a model of its world—it *is* a model. In other words, the form, structure, and states of our embodied brains do not contain a model of the sensorium—they *are* that model" (Friston 2013, 213).

Chambon and Haggard (2013) raise the question of how an ideomotor account would account for the issue of action selection. Friston et al. explain how this is done on an AIM account by framing the physiology of dopamine in Bayesian terms, such that dopamine controls the precisions of perceptual cues (Friston et al. 2012). The way dopamine does so is by mediating the affordances (i.e. action possibilities) of the cues that elicit motor behavior, which can analogously be understood in the same way that attention mediates the precision cues in the perceptual domain. Dopamine has a central role in balancing bottom-up sensory information and top-down prior beliefs when making hierarchical predictions about cues that have affordance and, in doing so, it becomes an implicit action selection process.

This would mean, as highlighted by Edwards et al. (2012), that, since the case of CP involves abnormal precisions of predictions, the attentional optimization of precision can be cast in terms of affordances. What has been learned when experiencing SoA in CP is different ways of experiencing affordances in the world. In contrast to CIM, here, the prior beliefs influence the action selection process, which means that, for people with CP, their sensorimotor control is based on actual motor learning and not on internal filtering by prior beliefs.

Whether or not predictions in AIM can in fact be interpreted in more 'external' terms, such as affordances, is part of the current discussion of defining AIM as either an embodied cognitive theory

(Bruineberg and Rietveld 2014) or not (Hohwy 2014). For such discussion and the further development of the discussion of motor control in SoA, we see the case of CP as an important and contributing factor. However, in doing so, we also see problems with CIM since it reduces the influence that actual motor control has for SoA. AIM provides an explanation of CP that requires further development but, as a point of departure, it avoids this problem in CIM. To interpret AIM in internal terms, such as Hohwy (2014) does, would nonetheless lead to the same problem as seen in CIM. Based on the case of CP, we therefore propose that the future development of the discussion of motor control in SoA is to be found in a more external reading of AIM.

## 7. Conclusion

In this chapter, we have discussed the three models, CM, CIM and AIM, in relation to the case of CP and, in doing so, have found that both CIM and AIM ultimately account for SoA in Bayesian and prospective terms. In comparison to CM, they operate with a notion of SoA that is a question of more or less. Nevertheless, CIM and AIM differ when it comes to the meaning of ‘motor control’ in relation to the issues of motor commands, predictions and motor learning, and we argue that AIM gives a more promising explanation of CP that preserves the influence of actual motor control in SoA. Thus, based on the case of CP, we propose that the future development of the discussion of motor control in SoA is to be found in AIM.

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## Chapter 6

### 'I Can, I Think': Bodily Certainty in Cerebral Palsy

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# 'I can, I think': Bodily Certainty in Cerebral Palsy

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## Abstract

The aim of the paper is to understand what can be called *bodily certainty*, which is an experience of certainty in one's ability to perform the action one intends to. The paper distinguishes between bodily certainty at the reflective level (*reflective bodily certainty*) and bodily certainty at the pre-reflective level (*pre-reflective bodily certainty*), and show how, in the literature, there is a tension and ambiguity in descriptions of the two. The paper presents a case study of the motor control disorder cerebral palsy (CP), in order to clarify both kinds of bodily certainty and the notion of '*bodily uncertainty*'. Bodily uncertainty is described as a disbelief in one's ability to perform the action one intends to, which arises due to introspective reflection and the exertion of rational control. Reflective bodily certainty is described as a sense of exerting control by embodied reflection, which contextualizes rational control and the beliefs of certainty in terms of situational control. Pre-reflective bodily certainty is described as a feeling of control, where the agent perceives the world in motor intentional terms and experiences that she can do something other than what she is currently doing. At the processing level of motor control, this pre-reflective bodily certainty is related to the precision (certainty) of the predictions of the forward model, as described in the embodied inference framework.

Key words: bodily certainty, bodily uncertainty, cerebral palsy, reflection, pre-reflective experience, sense of control, motor intentionality

## 1. Introduction: Bodily Certainty and Control

The aim of this paper is to understand the notion of 'certainty' that pertains to our daily actions. More specifically, the aim is to understand what can be called *bodily certainty*, which is an experience of certainty in one's ability to perform the action one intends to. Bodily certainty refers to the relation between one's intentions and actions, but we shouldn't conflate certainty with successful actions. One can act with an experience of bodily certainty, and yet fail to accomplish the action intended.<sup>38</sup> So, what does bodily certainty refer to?

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<sup>38</sup> Thanks to one reviewer for illustrating the need of making this point more explicit.

## 1.1. Certainty: Self-reflection or Trust?

Discussions in psychology have dealt with bodily certainty in the well-known theory of ‘self-efficacy’. In this theory we are not talking about certainty as ‘self-esteem’ or ‘self-confidence’, since these notions refer to the agent’s self-worth. Certainty refers to the strength of the agent’s personal beliefs in her ability to exercise some measure of control over her own functioning and over environmental events, so as to act out the effects that she intends to (Bandura 1997). The notions of ‘self-regulation’ and ‘resiliency’ are typically emphasized, so as to describe the abilities that the agent beliefs in. Self-regulation is the ability to self-regulate learning processes or emotions, where the former requires controlling and monitoring one’s own actions in order to meet goals of self-improvement (Paris & Paris 2001, 89), and the latter requires the monitoring, evaluating, and modifying of one’s emotional reactions in order to achieve one’s goals (Thompson 1994, 27-28). Resiliency refers to the dynamic ability to contextually modify one’s level of control as it may be appropriate or necessary according to the situational context (Letzring et al. 2005).

Thus, in the theory of self-efficacy we operate with a notion of ‘bodily certainty’ at the reflective level (*reflective bodily certainty*), where higher cognitive abilities and executive functions of control, monitoring and evaluation play a necessary role for acquiring such beliefs of certainty. In this description, there would be no motivational factors for acting if agents didn’t believe in their own abilities to exercise control (Bandura 2006, 170). Uncertainty is therefore described as a disbelief in one’s ability to exercise control in the case of surprise or difficulty.

Wittgenstein argues in his book, *On Certainty*, that we should distinguish between a notion of certainty relating to beliefs, knowledge claims and facts, and a notion relating to a kind of trust. The latter doesn’t justify by reason, but is founded and affirmed through how we act in our daily practice (Wittgenstein 1975, 148. See also 509). Inspired by Wittgenstein’s distinction, de Haan et al. (2013) argue for a notion of ‘certainty’ understood as trust and they do so by focusing on obsessive-compulsive disorder (OCD).

De Haan et al. describe patients with OCD as worrying excessively about, and having difficulty tolerating, their unwanted thoughts, fantasies and beliefs.<sup>39</sup> They argue that the obsessions have to do with the attitude that the patients take to their thoughts and actions, and, since they don’t trust them, there is a desire for absolute certainty, in which the patients pay extra attention to their thoughts, movements and actions and try to exert control over them (de Haan et al. 2013, 10). However, when the patients use reflection to acquire certainty it creates what de Haan et al. call a ‘hyper-reflective trap,’ where the attempt to achieve control by reflection counter-productively augments the experience of uncertainty (de Haan et al. 2013, 14). Thus, de Haan et al. argue that what the patients need isn’t to increase certainty by self-reflection,

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<sup>39</sup> See also Denys 2004 and 2011 for a similar description of OCD.

since that's actually part of the problem, i.e. the patients use 'too much reflection'. Instead, they need to learn to trust, which is understood as a feeling or experience of certainty in one's thoughts and actions.

Here the notion of 'uncertainty' refers to the patient's experience of 'estrangement', 'anxiety' and 'insecurity' in performing their actions (de Haan et al. 2013, 14). Carel have unified such experiences under the heading of 'bodily doubt,' which she describes as a disruption of the continuity of our lives, where our daily habits and normal flow of everyday activities are halted. The bodily doubt makes us become reflectively and explicitly conscious of our body and its abilities and the trust we normally had in the continued functioning of our body is weakened or, in the worst case, lost (Carel 2013).

In contrast to this experience of uncertainty (doubt), Carel describes the notion of 'bodily certainty,' as a experience of trust where we don't need to reflect, since the certainty is anchored in what Merleau-Ponty calls the 'habitual body' (Merleau-Ponty 1962, 95), i.e. the body's accumulated abilities, habits and routines (Carel 2013, 181). Bodily certainty is a tacit and *pre-reflective bodily sense of certainty*, where we feel confident that our body will continue to function as it has functioned in the past. This feeling, Carel emphasizes, grounds human existence, gives us a sense of stability and normality, and makes the world appear familiar and predictable (Carel 2013, 181. See also Ratcliffe 2008). Due to its habitual background, pre-reflective bodily certainty is in addition a feeling of possibility and ability to perform my actions, which Carel relates to the phenomenological notion of the 'I can' (Husserl, 1960).

In this description of pre-reflective bodily certainty, we see that trust is contrasted with self-reflection, since reflection is constitutive of bodily uncertainty (doubt). This description resonates with the description of reflective bodily certainty, since here uncertainty is also described at the reflective level, as a disbelief in one's ability to exercise control. However, when it comes to understand why the uncertainty arises and how to acquire bodily certainty there is a tension and ambiguity in the two descriptions. On the one hand, uncertainty arises due to too much reflection and a lack of trust, which means the agents need to disregard reflection and to learn to trust in order to acquire pre-reflective bodily certainty. On the other hand, uncertainty arises due to a disbelief in one's ability to exercise control, which means that one should work on the ability to self-reflect, self-monitor and self-control.

The reasons for this tension and ambiguous relation between reflection in bodily certainty and uncertainty in the two descriptions are unclear. First of all, what meant by reflection in the two descriptions? Are they talking about the same or different kinds of reflection? And what do de Haan et al. mean by 'too much reflection': how much is too much? Secondly, in the reflective descriptions, bodily certainty refers to the agent's ability to exert control, but in the pre-reflective it's unclear what kind of ability they are acquiring when they learn to trust.

## 1.2. Relating Intention and Control

One way to start answering these questions is by distinguishing between two different ways of experiencing control in pre-reflective and reflective bodily certainty. Pacherie has recently distinguished between the sense of control where 1) one *feels in control* and 2) where one has the *sense of exerting control* (Pacherie 2007, 18). The former refers to the experience of control wherein one feels that an action happens exactly as expected, that one is fully in control and there are no perturbing factors. Perturbations may, nonetheless, occur due to external or internal factors and may require either physical or mental effort. The sense of exerting control is therefore experienced as effortful, since the agent has to exert control in order to overcome perturbing factors and perform the intended action. Normally, the relation between the two senses of control is gradual and the more one feels in control the less one experiences the sense of exerting control, and vice-versa (Pacherie 2007, 18-20).

It would be fitting to relate pre-reflective bodily certainty to the feeling of control and reflective bodily certainty to the sense of exerting control, but the matter of understanding sense of control is more complex. Pacherie clarifies the two ways of experiencing control further by relating them to three different levels of intentions, namely future-directed intentions (F-Intentions), present-directed intentions (P-intentions), and motor intentions (M-intentions) (Pacherie 2007, 18-19).<sup>40</sup>

The F-intentions are formed prior to the actual action, and the deliberate formulation of the intentions is relatively abstract, conceptual and decontextualized from the action. The F-intentions represent the action as a whole and as an action plan. P-intentions serve to implement and contextualize the action plan clarified by the F-intentions. The translation of F-intentions into P-intentions occurs both in the time and situation of the action and transforms the action plan into perceptual and contextual content. M-intentions involve the transformation of the perceptual and contextual content of P-intentions into sensorimotor representations and a motor program (Pacherie 2007, 3).

Pacherie suggests that sense of control is a compound of these three levels of intentions, where it's possible to speak of rational control (F-intentions), situational control (P-intentions) and motor control (M-intentions). The sense of exerting control relates specifically to the F- and P-intentions and should be understood as a higher-level guidance and control function involved in the rational and situational control of action. Here the F- and P-intentions support control processes by keeping track of the way the agent accomplishes her action and adjust the actions so as to maximize chances of success (tracking control) and to minimize undesirable sideeffects (collateral control). The main difference between F-intentions and P-intentions is that the former are concerned with the agent's rational judgments of the action's global

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<sup>40</sup> The distinction between F- and P-intentions is inspired by Searle's (1983) distinction between 'prior intentions' and 'intentions-in-action', and Bratman's (1987) distinction between future-directed and present directed intentions.

consistency and coherence constraints. The latter is a situational control where the exercise of tracking and collateral control refer to the situation as currently perceived (Pacherie 2007, 4; see also Pacherie 2006, 150).

The sense of feeling control is a weighted result of both F- and P-intentions and M-intentions, and where there is no need for exercising control (Pacherie 2007, 21). The role played by M-intentions is that of motor control, which Pacherie describes as automatic and unconscious, and it's only when the motor adjustments and corrections become too large to automatically correct that control at this level becomes conscious (Pacherie 2007, 19).

How does Pacherie's description of sense of control relate to the descriptions of pre-reflective and reflective bodily certainty? Reflective bodily certainty is to be understood as one's beliefs in the ability to exercise measures of control. This is acquired at a reflective level by both adjusting the F-intentions and/or through the ability to track, monitor and self-examine in the actual situation of performing the action (P-intentions).

However, where does pre-reflective bodily certainty fit in this description? Here we are not talking about bodily certainty at a reflective level, which means it's not the sense of exerting control. The feeling of control supposedly refers to all three levels of intention, which means that if pre-reflective bodily certainty is to be described as a feeling of control, one must describe the relation between rational, situational, and motor control at a pre-reflective level. Furthermore, in the reflective description of bodily certainty the sense of exerting control by reflective means leads to bodily certainty, so we also need further clarification as to why 'too much reflection' leads to bodily uncertainty.

I will look at the case of cerebral palsy in order to provide such description of pre-reflective bodily certainty as feeling of control and further clarify why reflection sometimes leads to bodily uncertainty.

## 2. The Case of Cerebral Palsy

As an umbrella term, Cerebral Palsy (CP) is defined as a group of disorders affecting the development of postural and motor control, occurring as a result of a non-progressive lesion in the developing central nervous system (Bax et al. 2005). In 90 % of the cases, the lesion occurs during pregnancy (Ellenberg & Nelson 2013), making CP the most common type of disorder associated with lifelong motor impairment (Aisen et al. 2011). At the same time, CP is a heterogeneous condition that varies according to the particular brain lesion and individual in question. As a result, CP is typically classified according to its different types of motor symptoms (spastic, dyskinetic, or ataxic) and to the bodily location of the motor impairment (mono-, hemi-, para-, and tetraplegia). Spasticity is seen in most cases of CP, where the lesion affects the upper motor neurons, damaging the motor neurons' ability to regulate descending motor pathways, which results in

overactivity of the muscles (e.g. exaggerated tendon reflexes and hypertonia) (Dietz & Sinkjaer 2007; Sheean & McGuire 2009).

The focus in this paper is on spastic CP, and a recent definition of spasticity defines it in terms of involuntary movements as “[d]isordered sensory-motor control, resulting from an upper motor neuron lesion, presenting as intermittent or sustained involuntary activation of muscles” (Pandyan et al. 2005, 5). The main question is, therefore: *What is the experience of bodily certainty and uncertainty like, while living with involuntary movements?*

## 2.1 Interview Design: First-Person Experiences of Living with CP

Only a modest number of studies have previously investigated the first-person experiences of living with CP (e.g. Sandström 2007; Peckitt et al. 2013), but in Martiny 2015 the author presents phenomenological interviews with adults with spastic CP. The overall design and analysis of the interviews is inspired by phenomenological research, and uses the interview method called *Explicitation Interview* as an interview technique (Vermersch 1999, 2009; Petitmengin-Peugeot 1999; Petitmengin 2006; Petitmengin & Bitbol 2009; Bitbol & Petitmengin 2013). This is a second-person semi-structured interview method with its own specific questioning and analysis techniques, which use open ‘how’ questions and specific strategies to draw the attention of the interviewees to detailed aspects of their experience, making them able to give detailed first-person descriptions of their lived experiences. In this case, the focus is on how persons with CP experience themselves and their own bodies while performing daily actions. For a full account of the interview design and methodological considerations, see Høffding and Martiny (forthcoming).<sup>41</sup>

The interviews were done over a period of one year and took place at the Helene Elsass Center (HEC), a Danish habilitation center working primarily with CP. The participants were part of a habilitation project focusing on the effects of intensive strength training. Out of the 20 participants taking part in the strength training project, 14 participants (7 women, 7 men, age 23-57) were selected for the interviews by focusing on spastic CP. The 14 participants represented the diversity of spastic CP to a great extent, since the group included participants with a diverse range in the nature and degree of severity of bodily impairment. In relation to the gross motor function classification system (GMFCS) developed for children with CP, the participants in the study correlated to Level I-IV (Palisano et al. 1997).

The interviews varied from one to two hours, depending on the participant, and 4 out of the 14 participants were interviewed more than once, due to either time restrictions in the first interview or in order to gain further elaboration of descriptions from the first interview. Working at the HEC, both before and after

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<sup>41</sup> See chapter 3 in this Ph.D. dissertation.

the interviews, made it possible not only to observe the participants and talk more informally with them about their experiences of living with CP, but to talk with other persons with CP, their relatives and the HEC's healthcare professionals.

### **3. Results: Bodily Experiences in Cerebral Palsy**

Different kinds of involuntary movements are described by the participants. Some involuntary movements occur without the person experiencing the movements happening, and are typically pointed out by other people, and some relate to the experience of shock that comes from a hypersensitivity to external information, primarily sounds. The participants also describe a kind of involuntary movement, which relates specifically to their performance of intentional actions. These movements are the focus of this case study.

#### **3.1 The Bodily Experience of Involuntary Movements**

Such involuntary movements are described as follows by MS, a 26-year-old man with spastic hemiplegia in his left side:

“I experience a bit of tension, which makes it difficult for me to perform the actions that I want to do. So it makes it a bit involuntary, you can say... It doesn't have to be that much, but it can just be a small degree, which brings about the actual effect that I become uncertain and therefore ask for a helping hand”

MS describes the movements as being involuntary, since they complicate his performance of the action he intends to do, creating an uncertainty in his actions. In some cases, the involuntary movements result in the inability to act, as FN, a 39-year-old spastic tetraplegic, describes in an example of riding a bike:

“So if you are trying to get your legs moving when riding a bike there is always the experience of resistance in doing the movement, and although I think: ‘come on, increase the pace’, because I feel I can do it in my body and my head, it's not what my legs are doing. They have their own pace, and sometimes I experience that if I try to force them, then the stiffness, the spasticity, works against me...In the end I'm totally stiff and I stop completely.”

HJ, a 48-year-old spastic paraplegic, uses an analogy in order to clarify the experience of bodily tension while performing actions:

“it's like, for example, if you try to clutch your hand, but then at the same time have to use it while it's clutched. I'm exaggerating, but that's how I experience it, a little in my hands, but especially in my legs. That's part of it, and then I also experience that there are movements I don't know how to make, for example, in asking my foot to do something...I can see other people can make this movement, and then I think I should be physically able to do it. I look at my foot and say: ‘okay, move upwards’, but I can't. I'm not able to figure out how to do it.”



HJ's description points to the fact that, through observation of other people's movements and actions, he has come to acknowledge that there are simple daily actions he doesn't know how to do.

Depending upon their degree of spasticity, resistance, tension, stiffness and the bodily location of the impairments, the participants describe different aspects of uncertainty in typical daily actions. A common feature of the descriptions is that they make reference to crucial abilities for performing daily actions, such as keeping balance while walking or performing fine motor control over the movements of one's fingers while making dinner or putting on clothes. HJ describes the experience of uncertainty by emphasizing the action of walking:

"[t]here is always an element of something like uncertainty or whatever you would call it. There is always an element of constant adjustment. It's difficult to explain. Call it reaction, which is that I have to react against my own body. It's like the difference between if you walk normally and if you walk with weights on your feet. I just don't have anything to compare it to, since I haven't had the weights off my feet. I can just see that everything is more difficult for me than for everyone else... Typical daily tasks just take more time, either because I have to do it in a different way than you do or because I become tired more easily than you."

HJ also uses the analogy of having weights on his feet to capture the difference between walking 'normally' and his way of walking, which comparatively seems to take more time and be more exhausting.

TN, a 38-year-old man and spastic hemiplegic, comments on the difference in time that elapses between his intention and action: "I'm born with a small brain damage, which makes the relation between my thought and action longer for me than for others." This refers, first of all, to the fact that it takes a longer time to perform the actual movements intended than it 'normally' would. Secondly, the slower passage from intention to action relates to longer reaction times, which leads to problems in the adjustment of the movements. As DM, a 42-years-old woman and spastic paraplegic, says:

"I don't experience that [my body] is profoundly unpredictable, since I know what goes wrong when I fall. The problem is that I don't manage to correct [my body] in time... I usually manage to sense what is happening. This is the reason why I'm extremely aware of my left leg, which causes the problems. But sometimes I cannot manage to correct it in time. If I just could think 'oh no I'm falling' and then find my balance again. But I cannot."

From these descriptions, we see that there is a close relation between the participants' involuntary movements and their description of their experience of uncertainty. This experience of uncertainty is related to the relation between intention and action. An overall summary of these aspects of living with CP is given by NJ, a 25-year-old man with spastic tetraplegia:

"I experience an uncertainty in my actions... I experience a divergence between what I want to do and what I can do. I can drink a glass of water, but I also know that 1 out of 10 times I'll choke on the water or spill it, and that

creates an uncertainty in me. I think it creates a disbelief in my actions and that's difficult to do something about, because that's just the way it is. So, I experience a divergence between what I want to do, what I can do, and what I do."

### 3.2. Action Strategies and Planning

Although involuntary movements inhibit their action performance, all the participants describe how they have developed specific ways to act and to deal with the accompanying experiences of uncertainty. For completing actions successfully, practice and learning is necessary, as it is for any person. Nevertheless, there is a fragile relation between learning and action in CP, as FN describes in her experience of riding her bike to work:

"[i]t's something like being a child and having to learn something new. I do experience that my body and my brain have tried the movements before, and it would of course take a lot longer if I hadn't biked before, but basically the feeling I have in my body is like starting from the very beginning again.... You don't have to think when you take a step or use your arm or something, whereas I can feel that I need to use more thought capacity... This contributes to the experience that I'm tired in my head, probably because I use extra energy in doing normal and daily things, which you don't have to think about in the same way."

Despite knowing how to bike, the constant occurrence of involuntary movements and spasticity makes it difficult for FN to complete her action. FN has to therefore use an enormous amount of cognitive energy in order to be able to bike and accomplish her other daily activities.

The other participants also give such descriptions of using a lot of cognitive energy to perform their actions. NJ gives an example of how he walks:

"[i]t's not because we [CPs] think about everything, but we just use more energy and strength to think about, for example, not falling or looking at where we are going. I'm not good at compensating when I walk, because I use extra strength not to fall between the bike lane and the pavement, and I have to lift my feet high. I'm not good at having deep conversations when I walk and that's an expression for the fact that sure I can walk and I don't really think about it, but I think about it more than others."

LJ, a 58-year-old spastic paraplegic, gives a similar description of walking and calls it a way of 'walking with your head.' As a result of having to use a lot of energy when performing their actions, the participants have developed specific strategies for doing so. As NJ says: "We have to reinvent our own way and it takes, no matter what, more energy to reinvent something than to imitate everybody else... So we get the same output, but the way may be a different one than for others." Part of their strategy includes extensive planning and predicting the effects of their daily actions in order to avoid using too much energy and making too

many unnecessary mistakes. MB, a 33-year-old man with spastic monoplegia in his right legs, describes it as follows:

“I see myself as being a lot more predictive than many others. I try to think [an action] through before I do it. I try to have a strategy for how I do things. It’s a mental process and it’s to prepare myself, so that I can do things in the best way possible.”

NJ gives a general description of the need for action and predictive strategies in living with CP:

“When I act in places I’m used to, I can minimize uncertainties. It really reduces my impulsive presence, and I think in a way that CPs and other people with disabilities are very present, because they use a lot of focus on having social contact, but on the other hand we are very distant, because we use a lot of energy to think like, ‘what if this is going to happen.’ For me it’s about being one step ahead. It’s knowing what’s going to happen and then compensating. I think in situations I’m used to, it becomes a habit and things I just do. I can really feel when I’m in situations I’m not used to; then it really goes downhill fast. At home I’ve learnt to incorporate all these compensations; outside it’s just more difficult.”

All the participants describe, as NJ does, that outside everything is just more complicated. Examples of going shopping for groceries in the supermarket or going to a party with friends or family are described as exhausting and just the thought of doing so introduces experiences of uncertainty. This is different from the situations they are used to, which is usually when being at home, where the involuntary movements have become a habit. Many of the participants therefore describe that they experience more at ease and more certain in being at home, than outside in the social world.

### 3.3 Certain Uncertainty

From the very beginning of the interviews, when asked broad questions, like “can you describe how you experience living with CP in your daily life?”, all of the participants emphasized the problem of actually describing living with CP, since it’s congenital. This is already seen in some of the descriptions above where the participants emphasize that they haven’t tried anything else than living with CP and that they don’t have anything to compare it to. There is no experiential ‘before or after’ in congenital cases.

This means also that in some of their daily actions, the participants describe that they don’t necessarily experience their involuntary movements as uncertain or problematic. As MP, a 31-year-old woman with spastic paraplegia, says: “I don’t think that I’ve thought that much about something being different. It probably has something to do with the fact that when you have learned something, then that’s the way you are going to do it.” MS was in a wheelchair until the age of 12, and he describes how he learned to walk and perform difficult actions by saying that “the more repetitions of an action, the more certain I am in doing the

action, the more I'm in control of the action, the more I relax and then I don't experience the spasticity as much." This means that, although involuntary movements are a crucial part of the participants' lives, not all their actions are felt as exhausting and something they need to forcefully perform. TV, a 28-year-old man with spastic diplegia says, while addressing the interviewer:

"you would probably be better at noticing [my involuntary movements], because I don't experience them, and that has something to do with the fact that it has always been like that for me.... It's like people that have tinnitus, I guess, since if they have had it for a long enough period of time, then it's possible to have the ringing noise, without them reflecting upon it. So, it has to do with your preconditions."

This means that, although most of the participants point out that there are experiences of uncertainty related to their involuntary movements, they all describe how they have learned to attune to such uncertainties. As NJ describes it:

"I have gotten used to my body being uncertain, so, by contrast, I would say that I experience being in full control of both my body and thoughts in the way that I have become more aware of how my body works. It may sound strange, but if you don't get fixed on all the uncertainties and mistakes I make, it actually means that I've used so much time and effort to refine these complications...I actually know my arsenal of complications."

This way of acquiring certainty may require a lot of cognitive energy, as we have already seen, but, as MS says, it is gradually related to the way he believes people normally act:

"[m]y body does what I want it to do and I know the actions that are difficult. I can act before they happen, before it becomes a problem. But it's a question of degree...I have to correct my movements, when something unexpected happens, but everybody has to do that. I just have to do it to a much larger degree."

As a result, HJ wouldn't use a term like 'uncertainty' to describe his own bodily experiences:

"I don't have anything [to] compare [my body] to. If we need to say something is uncertain, we need to know what is certain, and I don't know that, because I haven't had any other bodies than this one. So I don't have anything to compare it to and so I won't call it uncertain, because I have the parameters I have. But if I look at other people and I look at what I can and they can, I see there is a difference. In this way it's uncertain. But my own personal experience of my body is like it is."

## 4. Discussion: Embodying Uncertainty

The reason for looking at the case of CP was to provide a description of pre-reflective bodily certainty as a feeling of control, and to further clarify why reflection sometimes lead to bodily certainty and other times to

bodily uncertainty. I will discuss the participants' descriptions of their experience of bodily certainty and uncertainty with the aim of providing such description and clarification.

#### 4.1. Reflective Uncertainty

As seen in the descriptions above, due to the congenital nature of CP the participants have a tendency to understand themselves and explain their experience as they think their experiences must be. This is typically done by analogies or by differentiating and understanding their experiences in relation to how they think the bodily experiences of 'normal' persons are (see also Martiny 2015).<sup>42</sup> In some cases, they see people perform actions they believe they should be able to do, but then continuously fail to do them. If they try to force their movements this only makes the spasticity increase, which may result in the inability to act at all. The participants therefore describe a close relation between their involuntary movements and the experience of bodily uncertainty.

These descriptions of uncertainty illustrate a disrupted relation between intentions and actions, but they do so, at the reflective level. The participants describe that their involuntary movements make them become reflectively aware of their body, where they experience bodily tensions, resistance and stiffness, experience being weighted down, and experience that their body takes longer time to respond than others. One participant describes that due to his involuntary movements he experiences a divergence between what he wants to do and what he can do, and this creates a disbelief in his actions. So, as it is presented in both descriptions of pre-reflective and reflective bodily certainty, bodily uncertainty in CP is reflectively experienced, where the participants become reflectively aware of their body and experience a disbelief in their body. However, what is the relation between disbelief and reflection in uncertainty?

At the reflective level, as described above, part of bodily certainty concerns one's beliefs, F-intentions and rational control of the action's global consistency and coherence with how one understand oneself as an agent. A way to describe how reflection leads to uncertainty in CP is therefore, as Levy and Bayne have done in relation to OCD and Tourette's syndrome, by describing it as failures of inhibition (Levy & Bayne 2004, 465-466). Such failures occur when the agent has lost rational control over their actions, but the actions, nonetheless, can be ascribed to the agent, since they are willed and performed for a reason. In OCD and Tourette's syndrome, the agents perform their actions as a result of consciously 'giving in', in order to relieve the increasing discomfort that continued resistance causes in them. However, the patients don't identify with the actions they perform, since they perform them only to relieve discomfort (Levy & Bayne 2004, 466).

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<sup>42</sup> See chapter 4 in this Ph.D. dissertation.

The problem with giving such a description of bodily uncertainty in CP is that the failures of inhibition do not occur, because of a loss of rational control, since the persons with CP do in fact identify with their actions. In contrast, the problem is that some actions they perform, because they ‘rationally’ believe they can do them and they identify with them, but they are, nonetheless, not able to perform the actions. There is a ‘divergence,’ as one participant describes it, between what they want to do (F-intentions), what they can do (abilities) and what they perform (actions). It’s this divergence that is the source of their bodily uncertainty, which creates a disbelief in their ability to perform the actions that they want to.

However, exerting control and acquiring a reflective bodily certainty are not just about believing in one’s abilities, since everyone can have wrong beliefs about one’s abilities. In exerting control, the rational aspect of control should be related to the situational aspect of control (P-intentions), which is the ability to exercise tracking and collateral control in the actual situation of performing the action. Contrary to Levy and Bayne’s interpretation of OCD, de Haan et al. (forthcoming) argue that, due to the lack of trust in OCD, there is a tendency for patients to rationally exert control over their actions, which then leads to bodily uncertainty. The tendency to exert control in this way is part of the same process as reflectively directing one’s attention ‘inwards’ to one’s movements, actions and thoughts, instead of outwards towards the world. Relying solely on rationally controlling one’s performance of an action self-distances one from the actual experience of acting. Instead of opening up possibilities for action, the patients become ‘trapped in themselves’ so to speak, and their ability to perceive other possibilities for engaging with the world is decreased. The ability to perceive possibilities requires an attitude of acceptance, a basic trust, which opens up the world instead of closing it off (de Haan et al. forthcoming, 8).

The argument here is that the failures of inhibition in OCD are not because of a loss of rational control, but because the rational control is not situated, so as to exert control of the actions in the actual situation. This can also be seen in the case of CP, where the participant describe their body as having a life of its own and if they try to force their body the spasticity increases and it may end in the inability to act. Here the F-intentions are not translated into P-intentions. This kind of rational control relates to a specific reflective self-distancing from the actual performance of the action. In order for us to evaluate ongoing activities in this kind of reflection, we distance, observe and confront ourselves. Such reflective self-distancing can be called *introspective reflection* (Gallagher 2012, 16), which means that it’s not too much reflection (hyper-reflection) that leads to bodily uncertainty in either CP or OCD. Rather it’s the kind of reflection that the agents use to exert control, namely introspective and decontextualized reflection.

When the agents then self-examine the actions over which they have tried to exert rational control, they experience not being fully able to perform their actions, which might lead to the further exertion of rational control when performing similar actions in the future. This creates a disbelief in performing the actions, a

bodily uncertainty, and, in some cases, encloses agents in a hyperreflective trap, which keeps them trapped in such disbelief and bodily uncertainty.

## 4.2 Situating Reflection

In actions where there is a successful translation of F-intentions into P-intentions, and the action outcome matches the intentions, the sense of exerting control is accompanied by a reflective bodily certainty. Here, the agent progresses from the exertion solely of rational control to the exertion of both rational and situational control. This is seen in actions where the participants with CP experience reflective bodily certainty, despite having to exert control. The rational control refers to their extensive planning and predicting of the effects of their daily actions, as well as to their creative reinventions of how to perform the actions that they want to do. The situational control refers to how the participants in the actual performance of the action reflect on their body in order to be able to perform the actions. Exerting control in this way is related to the participants' abilities to self-regulate and be resilient, so as to achieve their goals.

But, as mentioned by one participant, in actions performed for the first time or in new places the F- and P-intentions can come apart, and the sense of exerting control occurs together with a bodily uncertainty. Depending on the kind of reflection that the agent uses to exert control, it might lead to either bodily certainty or uncertainty. What is the difference between reflection that comprises situational control and bodily certainty, and the introspective reflection, which doesn't?

Gallagher and others have emphasized that reflection comes in different varieties (Varela et al. 1991, Gallagher & Marcel 1999; Zahavi 1999, 2005, 2011; Gallagher 2012). Another kind of reflection than introspection is *embodied reflection*, where the mode of reflection is still observational, but not self-distancing.<sup>43</sup> According to Gallagher and Marcel, in this kind of reflection

"I start to think matters through in terms of possible actions. I treat myself (I discover myself) as an agent. In such situations, my attention is directed not in a reflective introspection of consciousness as consciousness, but toward my own activities in the world where my intentions are already directed. Often my aim in such reflection is not to represent my 'self' to myself, as if it were a piece of furniture in my mind, but to continue certain actions or to explain myself in terms of my actions" (Gallagher and Marcel 1999, 25).

In this kind of embodied reflection I situate my reflection on my embodied abilities and on my goal of the action in the immediate environment (Gallagher 2012, 16). The function of this embodied reflection is therefore to illuminate the pre-reflective bodily experience reflected upon and can be clarified with the

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<sup>43</sup> This kind of reflection can be defined in different ways. Zahavi (2005, 86-89) refers to Fink and Sartre's descriptions, where Fink describes it as intensifying pre-reflective self-awareness and Sartre as pure reflection, which imbues ordinary reflection with extraordinary qualities (Zahavi 2005, 86-89). Varela et al. call it embodied reflection (1991, 27-31), which is the notion I'll adopt, whereas Gallagher and Marcel call it embedded reflection (1999, 25) and Gallagher calls it situated reflection (2012, 16).

notion of ‘pre-reflective pragmatic self-awareness’ (Gallagher, 2005, 46). This form of pre-reflective self-awareness is, according to Gallagher, “tied to my embodied capabilities for movement and action” (Gallagher, 2005, 74) and, here, bodily self-awareness is not described “in terms that are explicitly about body parts, but in terms closer to the goal of the action” (Gallagher, 2005, 73). What this suggests is that, in embodied reflection, the body, or its parts, are not experienced as an objectification of or a self-distancing from bodily experience. The body is experienced as related to the subject’s ability to act and to the goal of the action, and the mode of the reflection is that of illuminating possibilities for action in the situation.

As seen in the participants’ descriptions they use embodied reflection in a way that opens up actual possibilities for movement and action. In the example given of walking the participants describe that persons with CP ‘walk with their heads’, which doesn’t mean that they are thinking about their body or body parts while walking, but about how to perform their actions, so that it makes it possible for them to walk. It’s in this sense of illuminating the participants’ abilities and possibilities for action that embodied reflection creates reflective bodily certainty in their actions. It’s the pragmatic contextualization of the reflection and the translation of F-intentions into P-intentions that not only gives the participants the ability to walk, but also grounds the belief of self-efficacy in the actual action of walking. So, the combined ability to rationally and situationally exert control gives the participants a belief of self-efficacy and a reflective bodily certainty.

However, embodied reflection in the case of CP is different from the way in which it ‘normally’ occurs, since their involuntary movements are an unavoidable part of their daily life. In many of their actions, they experience a need to exert control in order to successfully perform their actions. This is not to say, as the participants describe, that they don’t experience a feeling of having control over their actions. They also experience, like ‘normal’ people, being fully in control and having pre-reflective bodily certainty in their actions. Thus, the embodied reflection of people with CP is not different in kind from normal cases, but differs in extent, given that pre-reflective bodily certainty occurs less frequently in their daily actions. Nevertheless, the question is: how should we understand this pre-reflective bodily certainty?

### 4.3. Motor Intentionality

In contrast to the sense of exerting control, which refers solely to rational and situational control (F- and P-intentions), the feeling of control additionally comprises motor control (M-intentions). So, as mentioned, if pre-reflective bodily certainty is to be described as a feeling of control, we need to describe the relation between rational, situational and motor control.

De Haan et al. (forthcoming, 5) and Carel (2013, 182) describe pre-reflective bodily certainty in terms of habitual actions and skill acquisition. For Carel habitual actions are not optional, but a basic mode of action that takes agency for granted. It is simply the immediacy and automatic manner in which we turn to familiar tasks (Carel 2013, 182). This description of pre-reflective bodily certainty agrees with Pacherie’s description



of M-intentions, namely as automatic and unconscious (Pacherie 2007, 19). However, if we are to relate pre-reflective bodily certainty to motor control processes, we need to acknowledge that the notion of ‘pre-reflection’ refers to a conscious dimension and to something being experienced, sensed and felt (Zahavi 2011). It is problematic to relate pre-reflective bodily certainty to M-intentions, seeing as they are explained at the unconscious level. De Haan et al. also emphasize the point that in understanding the relation of pre-reflective bodily certainty and motor control processes, we are not dealing with phenomenology, but with a causal level of analysis of why bodily uncertainty arises in the first place (de Haan et al. 2013, 10).

However, a fundamental point in phenomenology is that a constitutive relation exists between motor control processes and pre-reflective aspects of bodily self-awareness (Merleau-Ponty 1962; Gallagher 2000, 2005; Legrand 2006; Gallagher & Zahavi 2008). The reason why Merleau-Ponty introduced the notion of ‘motor intentionality,’ was as a way to describe pre-reflective aspects of embodiment as comprising something between third person mechanistic processes and intellectualistic representation (Merleau-Ponty 1962, 126–127). Using the terminology in this paper, motor intentionality is something between automatic and unconscious M-intentions and conscious F- and P-intentions.

Merleau-Ponty describes his notion of ‘motor intentionality’, as where we perceive the world as ‘poles of actions’ (Merleau-Ponty 1962, 122). This means that, when we act, we don’t need to stop, reflect and generate F- or P-intentions for actions, since we already perceive our intentions for acting. The world shows itself and is structured as a medium for possible actions and potential movements. At the pre-reflective level, the motivational and initiating factors for actions are in the world, and we experience the world as having a value or meaning for us in terms of our interaction with it. This value is defined by the background made up of our habits, bodily skills and actual engagement with the world, but also by the intentional aspect of our action, namely its goal. This means that goals specified at the reflective level of F- and P-intentions influence the way we pre-reflectively experience the world.

The difficulty of understanding the notion of ‘motor intentionality’ is that in the dominating comparator model (CM), which Pacherie (2006, 2007) adopts, skillful motor control is a matter of learning internal models (the inverse and forward models) of the external world (Kawato 1999; Wolpert & Kawato 1998; Wolpert et al. 2001). De Haan et al. hypothesize that, at the causal level of analysis, the reason why persons with OCD experience bodily uncertainty could be a result of disorder of such feed-forward mechanisms (de Haan et al. 2013, 10). This hypothesis would make sense also in relation to CP, since part of the motor control disorder is, as mentioned, that the motor neurons’ ability to regulate the descending motor pathways (efferent signals) is damaged.

However, the problem is that within CM it’s not possible to understand why the persons with CP sometimes do experience pre-reflective bodily certainty and a feeling of control, since in CP there is no motor comparison. In involuntary movements, no motor command is issued, no efference copy is made of

the command and, therefore, no comparison is possible. The problem with the CM model is that it internalizes motor control processes, which means motor control becomes a matter of transforming mental processes (F- and P-intention formations) into brain processes (M-intentions). Nevertheless, as both Legrand (2006, 113-114) and Gallagher (2013) have argued, in order for this to be a phenomenological grounded model of motor control, we need to anchor and push the model back into the world.

Instead, I suggest using a recent account of motor control, called ‘Active Inference’ (Friston 2009; Adams et al. 2013) or ‘Embodied Inference’ (Friston et al. 2013). This is an account already in the world, which gives an explanation as to how motor intentionality is in fact possible. Here, predictions in the motor system encode the perceptual and sensory consequences of actions, which comprise the intention to act (Adams et al. 2013). In contrast to CM, the perceptual and motor systems go hand in hand and the striate (visual) cortex should be taken as being just as much of a motor cortical area as is the primary motor cortex (Friston et al. 2010, 2011; Adams et al. 2013). The awareness of the motor intention is therefore a perceptual sense of the effect want to elicit, rather than a motoric urge to move. In other words, movements are specified “in terms of what we want to see, as opposed to what we want to do...” (Friston et al. 2010, 240. See also Edwards et al. 2012).

Interesting for the purpose of this paper is that, within the framework of embodied inference, the symptoms of CP, such as spasticity, have been discussed as falling under what are called Functional Motor and Sensory Symptoms (FMSS) (Edwards et al. 2012). The overall idea is to explain these symptoms as abnormal precisions or uncertain predictions. A computational explanation of spastic CP within the framework is that “proprioceptive prediction errors retain a high precision but are not properly informed by descending predictions – leading to spastic paralysis” (Adams et al. 2013, 236). It’s the abnormality of so-called second-order prediction of precision that is at issue in CP. Pathologically high precision is given to intermediate predictions of movements, relative to higher (intentional) levels of the hierarchy. This means that, even though the prediction error isn’t being properly informed by descending predictions, it’s wrongly taken as a precise and highly weighted motor command. Thus, the motor system induces autonomous activity generating somatosensory and proprioceptive predictions that elicit a movement by classical reflex arcs. At the same time, the over-precise and overweighed prediction errors are passed forward to higher levels as movements not predicted by the higher hierarchical levels. This presumably causes the movements to be interpreted as involuntary and uncertain (Edwards et al. 2012), as also seen in the participants’ descriptions.

However, goals can be achieved in many different ways, depending on the context, but, at the pre-reflective level, there is a different direction of fit between intention and world than at the reflective level. At the pre-reflective level, we perceive the world in motor intentional terms, (re)acting intentionally to the world. We feel in control of these actions without exerting control, but by letting the world show the

possibilities of action and acting in accordance to them. At the reflective level, we make the world fit to pre-conceived F- or P-intentions, by exerting control of our movements and actions.

In order to be able to account for this, the embodied inference framework distinguishes between *actions* as states of the world and prior beliefs about future actions, which are understood as *control* states. The prediction of control depends on the precision of prior beliefs, which, in the cortex, is related to a top-down optimization process called attention (Feldman & Friston 2010). The notion of ‘attention’ is defined as the weighting of prediction error in relation to prior beliefs and action preparation, which can be influenced by the agent’s F-intentions and P-intentions. These intentions can help increase the gain of proprioceptive channels during motor preparation, and so one way in which the participants with CP feel in control of their movements should be understood in terms of the attentional optimization of precisions. The precision of prior beliefs is optimized so as to better predict the control of their actions and, therefore, they experience pre-reflective bodily certainty.

This would mean, as highlighted by Edwards et al. (2012), that, since the case of CP involves abnormal precisions of predictions, the attentional optimization of precision can be cast in terms of affordances. What has been learned when the participants experience pre-reflective bodily certainty and a feeling of control is different ways of experiencing affordances in the world.<sup>44</sup> We feel in control over our actions by experiencing the world in action possibilities and in being able to do something other than what we are currently doing, namely, by *being able to act otherwise*. The participants with CP describe it as being able to act and correct their movements before it becomes a problem and when they are able to do so, they don’t experience their involuntary movements as uncertain.

At the pre-reflective level, the world is experienced as a horizon of possible movements we are able to make (Husserl 1989, 228). Depending on what movement we make, the world will elicit other possible movements but, throughout all of these different movements and environmental changes, a sense that ‘I can’ do otherwise persists (Husserl 1960, 45, see also Husserl 1989, 270-271). Pre-reflective bodily certainty should be described as this persistent sense that ‘I can’ do otherwise and it can be understood within an embodied inference framework. Contrary to what Carel argue (the same argument presented by one of the reviewers), pre-reflective bodily certainty and a feeling of control is not non-optional or automatic, experienced as a feeling of being compelled to respond to the world in one specific way. It should not be understood in such static terms, but rather as a dynamical relation to the world that continuously changes whenever we move, making the world show new affordances for movement that we can (re)act to.

However, this feeling of control the participants with CP experience less frequently and it’s the feeling that patients with OCD typically lack. They have difficulty letting the world show them their possibilities for

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<sup>44</sup> The notion of motor intentionality can be related to the Gibsonian idea of ‘affordances’, but I won’t go further into this relation in the paper (see Rietveld 2012).

action and reacting to them. Not being able to move the focus from their movements to the world while acting, persons with CP typically have to exert reflective control over their movements. In doing so, they limit both their conscious experience of the world and the range of other possible movements.

Action difficulties and failures are always possible, but we nevertheless have a sense of bodily certainty in our daily actions, since we act in a way that, despite uncertain factors, shows us possible actions we are able to make. In some cases, there is no need for reflective aid when we encounter difficulties in acting. We rely solely on our habitual abilities and pre-reflectively feel in control and certain about our actions. In other cases, we can turn to our embodied reflective abilities, acquiring a reflective bodily certainty. All in all, we normally experience a certainty that we can perform the actions we intend to.

## 5. Conclusion

Based on a case study of CP, I have argued that it's not hyper-reflection as such that leads to bodily uncertainty, but the kind of introspective and decontextualized reflection that is used for exerting rationalized control over one's actions. Grounding one's belief of self-efficacy on such exertion of control won't lead to reflective bodily certainty, but can counter-productively lead to further bodily uncertainty. Another embodied kind of reflection contextualizes the reflection in terms of possibilities for action, which establish certainty in the situated performance of the action, as well as in the belief of self-efficacy based on these actions. This reflective bodily certainty is an embodied reflection.

Pre-reflective bodily certainty is related to a feeling of control, where the agent perceives the world in motor intentional terms. We feel in control of these actions without exerting control. We let the world reveal various possibilities for action and, despite uncertain factors, we experience that we can do otherwise. At the processing level of motor control, this is related to the precision (certainty) of the predictions of the forward model, as described in the embodied inference framework.

An overall proposal of this description of bodily certainty in CP is that, in relation to clinical practices that aim to work with the experience of bodily uncertainty in CP, embodying and situating rational control is necessary. This proposal can be strengthened by the argument that de Haan et al. propose in relation to OCD, namely that patients should work on letting go of exerting rational control over their actions (de Haan et al. forthcoming). How this embodied and situated proposal would translate into clinical practice is open to further development.

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## Chapter 7

# Engaging with Cerebral Palsy: To Help is to Collaborate

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# Engaging with Cerebral Palsy: To Help is to Collaborate

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## 1. Introduction

In this paper I will look at one exceptional case where two strangers engage face-to-face, namely a case where one of the strangers has cerebral palsy (CP). CP is a motor control disorder that makes it difficult for one to perform specific daily actions, and is therefore a disorder where successful performance of one's actions may require help from strangers. The case study consists of phenomenological interviews with 14 persons with CP, and 7 persons without CP, focusing on their experience of engagement when trying to help the person with CP.

I'll start by highlighting what can be called the *paradox of helping*, namely that, due to the nature of the exceptional social engagement, which is described as being uncertain for both strangers, the attempt to help becomes in many situations counterproductive and leads to action failures. The failure is due to *how* the action is performed and *how* the goal is achieved. In action failures the way to the goal is for both strangers experienced as uncertain, unpleasant, fearful or awkward. This means that the success of their engaged actions shouldn't be defined solely in terms of whether or not they complete the goal of, for example, walking down the stairs together. It concerns the way to the goal and the way in which they walk down the stairs together.

The interviews indicate that successful cases of helping are possible and I will discuss two possible ways to understand such engagement, as acts of *cooperation* or of *collaboration*. The notion of 'cooperation' and 'collaboration' are typically used interchangeably in cognitive science, but in order to understand the act of helping in the case of CP, the paper distinguishes the two, as has been done in e.g. computer, educational and organizational research (e.g. Hord 1986; Roschelle & Teasley 1995; Dillenbourg 1999). In this literature cooperation is described as a group of individuals solving distinct portions of a problem and collaboration is described as individuals collectively solving the problem together.

The overall aim of this paper is to describe the successful engagement between two strangers, one of whom, the one with CP, is in need of help as a case of collaboration. The overall argument is that collaboration can be described without referring to individuals' mental states, i.e. their intentions, goals, plans, desires, and motives, as it is done in the case of cooperation. Collaboration is understood as a process, which can arise without there being knowledge of such predefined intentional states. The experience of sharing a goal happens during the engagement, which, in the case CP, is a common goal of *how* to help the person with CP.

Trust is described as a necessary component of such collaborative engagement, since in trusting both strangers acquire control of the uncertain situation. Action difficulties and failures are always possible, and

also happen in many of the successful cases of engaging with CP. Nevertheless, when both persons trust each other, they experience a feeling of ‘we can’, which allows for risky decisions and action failures, and where both are motivated to continue the engagement until the common goal of helping the person with CP has been achieved.

## 2. Help: Cooperation or Collaboration?

The act of helping another person can be understood in many different ways. However, the case of helping a person with CP can be differentiated from what Warneken and Tomasello call *instrumental helping*, where the focus is on the action-goal, e.g. grasping a cup for a person that cannot reach it herself (Warneken & Tomasello 2007). In the case of CP the focus is not on the action-goal, but on the person with CP. Such case of helping could be understood as what Warneken and Tomasello call an act of ‘cooperation’.

### 2.1 Is Helping Cooperative?

There is no consensus on what is meant by ‘cooperation’, but one influential attempt is Bratman’s, wherein cooperation requires that a shared goal may be formed and that the subplans of each participating agent mesh towards intending that goal (Bratman 1992, 1993). Inspired by this definition, Warneken and Tomasello differentiate the act of instrumental helping from that of cooperation by studying 14 month-old children. Their results show that instrumental helping is easier for the children than cooperation, because the former only requires the understanding of what another individual intends to do. In contrast, in cooperation it’s not sufficient to understand the other’s intentions, since it’s necessary that this understanding is merged with one’s own intentions in order to form a shared goal and to mesh plans of actions toward that goal (Warneken & Tomasello 2007, 291).

This way of defining cooperation can generally be seen as the creation of shared (collective or joint) intentions (Gilbert 1989, 2000; Searle 1995; Toumela 1993, 2005). Sharing here is understood as the interrelation between the individuals’ intentional states. Cooperation is then only possible when the cooperating participants individually make plans to achieve the common goal and are able to make predictions about the intentions of others to achieve that same goal. Essential for this to happen is that the participants are able to infer each other’s intentions, thoughts and plans and combine them in their co-action in some shared way.

The so-called Interactive Turn in social cognition refers to a group of distinct views on social cognition, that despite their different specific takes on the phenomenon are united through a shared enemy, which typically goes by the name of the mindreading approach. The scholars discussing cooperation above can be seen as representatives of this approach, which, according to the interactive turn, read cognition in mental terms and

situate it within the skull. The mindreading approach adopt an observational and spectator stance for such reading, which is a stance characterized by ‘isolation paradigms’ and ‘experimental quarantines’ of passive observation (Becchio et al. 2010; Schilbach et al. 2013). The interactive turn therefore aims to develop a so-called second-person study of social cognition (Thompson 2001), which should include aspects of experiential and emotional engagement and reciprocal interaction when trying to understand and study social cognition (de Bruin et al 2012; Schilbach et al. 2013; Satne & Roepstorff 2015).

The phenomenon we are trying understand here is that of helping and a second-person study would be skeptical of describing the act of helping in cooperative terms, as seen above. Fantasia et al. discuss such definition of cooperation and try instead to give an enactive and second-person definition (Fantasia et al. 2014). They argue that cooperation is typically framed in full-blown, adult form that requires possessing mind-reading abilities, and abilities to align one’s own intentions and beliefs with the other’s. They want to present a milder, less cognitively weighted interpretation of cooperation, where shared intentionality is not explained from an observer’s perspective, but understood from a participant’s one. They end up describing cooperation as a process and emergent kind of phenomenon, which can arise without there being predefined intentions, motives to cooperate, or knowledge that the participants are cooperating. Shared goals may emerge during the course of the interaction (Fantasia et al. 2014, 3).

Fantasia et al. start their discussion by emphasizing Roschelle and Teasley’s (1995) influential definition of cooperation in order to support their position. However, Fantasia et al. overlook the fact that Roschelle and Teasley are not defining cooperation, but actually collaboration, and that they are doing so as an attempt to distinguish the two.

## 2.2 Is Helping Collaborative?

Typically in the literature of social cognition, the notions of ‘cooperation’ and ‘collaboration’ are used interchangeably. However, Roschelle and Teasley’s distinction between the two has been very influential in the literature of computer learning and education, where collaboration, and not cooperation as Fantasia et al. say, is defined as a “coordinated, synchronous activity that is the result of a continued attempt to construct and maintain a shared conception of a problem” (Roschelle & Teasley 1995, 70). Collaborative problem solving can be distinguished from cooperation, by distinguishing between a group of individuals solving distinct portions of a problem (cooperation) and individuals collectively solving the problem together (collaboration).

Collaboration should be understood as a process, an activity of continuously striving towards the participants’ mutual engagement, wherein they share an emergent, socially-negotiated set of knowledge elements. These elements constitute what Roschelle and Teasley call a Joint Problem Space (JPS), which is a “negotiated and shared conceptual space, constructed through the external mediational framework of shared

language, situation and activity – not merely *inside* the cognitive contents of each individual's head" (Roschelle & Teasley 1995, 71). Thus, the notion of 'collaboration' should not merely be understood in mental terms, such as presented in Waneken and Tomasello's discussion of cooperation.

However, it would be problematic to describe collaboration in terms of social interaction, as Fantasia et al. (2014) do in describing the act of cooperation. They use the notions of 'interaction' and 'engagement' interchangeably, as it is also typically done in the literature, but I take the notion of 'engagement' to mean something broader than interaction. In defending my position, I'll emphasize the recent definition of Satne and Roepstorff, which defines engagement as involving two aspects: 1) an experiential aspect and 2) a normative aspect (Satne & Roepstorff 2015, 19-20). The experiential aspect illustrates that engagement with others is an affective, emotional and reciprocal we-experience and that communication with others should also be understood in such terms.

The normative aspect of engagement, Satne and Roepstorff describe by emphasizing a phenomenological point, namely that engagement is fundamentally a mutual and interpersonal commitment. This means that what we experience in engaging with one another is the other as a person (Husserl 1989, 200). Satne and Roepstorff therefore problematize the definition of engagement as interaction, since there is a tendency in the interaction literature to describe the agents involved in these interactions as autonomous dynamical systems and/or biological organisms and not persons (Satne & Roepstorff 2015, 14). Satne and Roepstorff also problematize the definition of engagement as joint action. They point out that, in the debates on joint action, the dominating view is either to define engagement through notions such as 'shared intentions' and 'collective intentionality,' as seen above, or to appeal to lower-level mechanisms of coordination (Satne & Roepstorff 2015, 19).

In this the paper I will try to describe the act of helping in the case of CP as that of collaboration and I'll do so by developing this notion of 'engagement'.

### 3. The Case of Cerebral Palsy

As an umbrella term, Cerebral Palsy (CP) is defined as a group of disorders affecting the development of postural and motor control, occurring as a result of a non-progressive lesion in the developing central nervous system (Bax et al. 2005). In 90 % of the cases, the lesion occurs during pregnancy (Ellenberg & Nelson 2013), making CP the most common type of disorder associated with lifelong motor impairment (Aisen et al. 2011). At the same time, CP is a heterogeneous condition that varies according to the particular brain lesion and individual in question. As a result, CP is typically classified according to its different types of motor symptoms (spastic, dyskinetic, or ataxic) and to the bodily location of the motor impairment (mono-, hemi-, para-, and tetraplegia).

Spasticity is seen in most cases of CP, where the lesion affects the upper motor neurons, damaging the motor neurons' ability to regulate descending motor pathways, which results in muscular overactivity (e.g. exaggerated tendon reflexes and hypertonia) (Dietz & Sinkjaer 2007; Sheean & McGuire 2009). Thus, the current research and clinical focus for CP is invested in developing and optimizing antispasticity treatment protocols (Pandyan et al. 2005). Only a few studies have discussed the cognitive, emotional and social implications of living with CP, such as increased barriers and problems in social participation and peer relations for children with CP (Imms 2008; Bottcher 2010), or struggles in coping with a negative body image for adolescents with CP (Hammar et al. 2009). Research that focuses on the experiential as well as the cognitive and social aspects of living with CP as an adult is more or less non-existent (for one exception see Peckitt et al. 2013).

### 3.1 Interviewing Persons with and without CP

In order to understand the social implications of living with CP, this paper presents phenomenological interviews with persons with and without CP regarding their engagements. The interviews with the persons with CP were done over a period of one year and took place at the Helene Elsass Center (HEC), a Danish center working primarily with CP. The participants were part of a habilitation project focusing on the effects of intensive strength training. Out of the 20 participants taking part in the strength training project, 14 participants (7 women, 7 men, age 23-58) were selected for the interviews by focusing on the most common type of CP, spastic CP. These 14 participants represent the diversity of spastic CP to a great extent, since the group included participants with a diverse range of bodily impairments and with different degrees of severity of such impairments. In relation to the gross motor function classification system (GMFCS) developed for children with CP, the participants in the study correlate to Level I-IV (Palisano et al. 1997).

The interviews with persons without CP were done as part of a larger project focusing on how we encounter and engage with persons with CP and more generally with persons with physical disability (see Martiny et al in progress).<sup>45</sup> This project included a focus group of 15 Danes—8 women and 7 men between the ages of 22 and 59—who were chosen two weeks before the performance by randomly selecting people between the ages of 18 and 60 who were walking past the Royal Danish Theatre. Participants recruited were the ones that, after being informed that they were participating in a research project, still wanted to participate.

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<sup>45</sup> See chapter 9 in this Ph.D. dissertation.

The participants performed the social and psychological attitude test, Implicit Association Test (IAT) (Greenwald et al. 1998) in relation to physical disability, and answered a quantitative questionnaire, based on their experience of encountering and engaging with a person with CP. Out of the focus group, 7 participants, 4 women and 3 men, between 22-59 years old, were interviewed based on the results of the IAT test and their answers to the questionnaire. The interviews were done over a period of 2 months and took place at the Center for Subjectivity Research (CFS).

The overall design of the interviews and the analysis is inspired by phenomenological research, which uses semi-structured interviews as a methodological technique (e.g. Vermersch 1999, 2009; Petitmengin-Peugeot 1999; Petitmengin 2006; Petitmengin & Bitbol 2009; Bitbol & Petitmengin 2013). This interview method uses open ‘how’ questions and specific questioning strategies to draw the attention of interviewees to detailed aspects of their experience, thereby making them able to give detailed first-person descriptions of their lived experiences. In our case, the focus was on how the participants with and without CP experience their social engagement. The interview design of this study won’t be further described, but a full account of the methodological considerations is to be found in Høffding and Martiny (forthcoming).<sup>46</sup>

## 4. Results: The Experience of Engaging with CP

In the following I’ll present descriptions of the interviews done with both persons with and without CP. Although the descriptions were obtained in two different research projects they will be compared here, so as to understand what it means to engage with CP from the perspective of both persons with and without CP.

### 4.1. The Paradox of Helping

The primary engagement that the participants with and without CP describe in encountering each other as strangers is that of helping the person with CP in one way or the other. DM, a 42-year-old woman and spastic paraplegic, describes two different situations in which she is in need of help. The first refers to walking down a staircase:

“I find someone, who can give me a hand, even if it’s some random person on the street I approach them like, ‘excuse me, can you just...’ It doesn’t bother me, but it’s much worse if I fall on the street. Then I become very embarrassed and I can almost not bear if someone tries to help me up and sometimes that’s necessary, because I’ve actually been in situations where all of a sudden I can’t get up...And I can almost not look the person in the eye which I normally always do.”

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<sup>46</sup> See chapter 3 in this Ph.D. dissertation.

Persons with CP are used to asking strangers for help, since it's a large part of their daily life. In more extreme cases, such as getting up when one falls, they nevertheless describe the situation as 'embarrassing,' 'awkward' and 'unpleasant.'

When looking at how the participants without CP experience the situation, one sees the use of terms such as 'poor thing', 'mentally or physically slow' or 'weak' to describe the person with CP. The motivational factors for helping are therefore typically described in terms of 'benevolence', 'sympathy', 'being concerned for' or 'wanting to care for' the person with CP. AK, a 49-year-old woman without CP, gives the following description of the situation:

"It's just something about it being unfamiliar, a bit scary perhaps, it's unpleasant to watch, you are afraid that perhaps the person is suffering, that the person experiences pain... You are of course confronted with a human being that in some way, you believe, is locked in his own body, and you feel sorry for them."

"You are brought up to help people who have it difficult and it would be rude not to. You get uncomfortable when you see someone who has problems and you believe that it's a problem. What if they fall? So you better help them... It's a bit like when you ignore someone who is sitting and begging or something. You should really give him some money. He's sitting right there and you have seen him... You feel it unpleasant to do so, and that's how I feel, unpleasant, if there is a disabled person trying to get down the stairs."

In most cases of helping a person with CP the participants described it as a failure. MP, a 31-year-old woman with spastic paraplegia, describes how the situation of being helped in walking down the stairs becomes an unpleasant experience:

"If you ask people if they can just give you a hand down the stairs, then sometimes, because I believe they perhaps think, 'God, must I help her', they almost grab the entire arm. Then I say: 'look now I can't walk because your grip is too strong.' They will say: 'I need to get a proper hold of you.' But now I can't walk: 'You will have to trust me when I say you just have to give me an arm, or if you could just support the arm or just give me a hand, then I can do it, I'll even keep my balance down the stairs, you just need to get a hold.'... It's because they overdo it, so then it doesn't work. They almost make the situation much worse."

MB, a 23-year-old man without CP, gives a similar description and says that it's difficult for him to interact with persons with CP, because "I want to show this person that I respect him, which may seem a little forced sometimes, and then I overdo it, then you do it too much." LJ, a 58-year-old spastic paraplegic, clarifies that it's not the aspect of being touched by the other that leads to action failures, but it's the experience of uncertainty, the fear of falling, that makes the engagement problematic:

“I don’t mind being touched as such, but I’m afraid to fall...And the worst thing that people who have helped me can do is to help me up and then let me go. I always say ‘that’s fine, thank you for helping me up, but don’t let me go now, because I have to gather myself and figure out how to stand.’ So in that way I’m afraid when people come and if they give me a hug, for example, and then let go... I don’t like it, actually I don’t care for it...Because I think it’s awkward in some way to tell people that they need to let me go slowly.”

Action failures happen both in situations where the persons with CP make the initial approach and in situations where the persons without CP do so. The nature of the social situation is one in which both the person with and the one without CP experience uncertainty in the engagement. One aspect of the uncertainty relates to the difficulties of coordinating and correlating their movements and actions, which occur primarily due to the motor control disorder that the persons with CP have. On the one hand, the disorder makes it difficult for persons with CP to interact with persons without CP, since, as MM a 23-year-old man with hemiplegia in his left side describes, “they are, in both thought and actions, possibly two or three steps ahead of me. So interaction can be difficult, since it goes perhaps a bit too fast for me.” On the other hand, the motor control disorder makes it difficult for persons without CP to figure out what movements and actions they should perform, as FN, a 39-year-old spastic tetraplegic, describes it:

“It’s mostly with people who don’t know me that they can be uncertain or say things like ‘you should just tell me?’ and ‘where should I grab?’ or ‘how should I grab.’ I think they are afraid that it hurts, or that I’m made of glass or something like that”

As seen in FN’s description, one aspect of uncertainty relates to the coordination and correlation of the movements and actions, but another aspect of the uncertainty relates to how and the way in which they should engage with each other. AL, a 22-year-old woman without CP, describes her experience of uncertainty in how to act in the engagement:

“The problem is that I pity the person, and then, I think, I destroy the entire balance system between people...If you are different, then there is something there. I don’t know if I should compensate for it or accept it or how I should deal with this, because I don’t know how you feel. I can’t put myself in his place.”

AL’s description and the other descriptions above highlight the fact that the failure of the actions shouldn’t be defined solely in relation to whether or not the persons complete the goal of, for example, walking down the stairs together. The failure is due to *how* the action is performed, namely, whether the action is experienced as uncertain, unpleasant, fearful, pitiful or awkward, and whether the attempt to help counterproductively worsens the situation and then leads to action failures.



## 4.2 Difficulties in Communication and Understanding

BI, a 39-year-old woman without CP, describes that “it's easier to be with your family for example, than it is to be together with strangers, because then you must struggle to figure out how to behave and how they do it...Familiarity just makes things easier.” This is also described by the participants with CP, because, as MP who has CP, emphasizes:

“the people you associate with every day, they know you too well, so they know what you can and can't. You yourself have become familiar with living in a world where everyone knows you, where they know you well, and then they may not pay so much attention to [your CP].”

This knowledge of, and familiarity with, the person with CP is of course not possible in the engagement where both persons are strangers, and encountering a person with CP is very different than encountering another ‘normal’ stranger. JO, a 59-year-old man without CP, describes encountering a person with CP in the following way:

“[In the encounter] you've just been made aware that it's a completely different world. It's perhaps empathy, but [regardless of what type of experience it is] it's at least an experience. In the sense that I have difficulties putting myself in the position of not being able to control my pronunciation or control my body...I can't feel that. I can't put myself so much out of my own system, that I will understand it. I understand there is a difference.”

MB, without CP, clarifies the difficulties of understanding the person with CP in the encounter, by saying:

“Logically I can put myself in the position that it must be hard, but I don't think that you can really put yourself in their shoes if you haven't tried it...I've had some injuries, but it's not at all the same. With my heart or feelings I can't put myself in their position, but logically I can imagine that it must be very difficult and terrible in many ways.”

These descriptions are characteristic for the participants without CP, who stress that it's difficult for them to put themselves in the position of persons with CP, because living with CP seems to be so different from their own lives. However, this goes both ways, and HJ, a 48-year-old spastic paraplegic, describes his attempt to figure out how persons without CP walk as follows:

“I think about how it feels to walk without crutches, to being able to walk, to have a normal body. I would really like to experience that...I've been very reflective and tried to understand what people do when they walk, because I can't. I have to learn it consciously. When people who have full gait function learn to walk, they learn it at some point in their lives where they aren't very conscious, namely, when they are very young. So it's something you learn with your body, putting one foot in front of the other. When adult humans have to explain it to another adult, ‘what do you do when you walk?’ it becomes really difficult to explain, because it's just something they do.”

Problems with understanding one another may also be at stake in other cases where strangers try to engage, but here the strangers are able to communicate so as to figure out how to engage. One of the main problems in social engagement with persons with CP is that of communicating. Some persons with CP have a speech impediment and have difficulty controlling their facial and mouth muscles. Some might, in addition to a speech impediment, have cognitive difficulties but, as we will see, that's not the only problem for communication. Even for those persons with CP who do not have a speech impediment or cognitive difficulties, communication is a crucial problem.

AK, without CP, emphasizes verbal communication as crucial for her social engagement:

“Language means a lot to me, whether we can talk, if I can make myself understood, if a person understands me. Yes they [people with CP] probably do, but then they can't just react to what I say. We don't have any communication. We really don't have anything together. You just don't start to hold hands with someone you don't know. It's language, which is the first communication.”

MA, a 56-year-old woman with spastic tetraplegia, who has a speech impediment, describes her experience of talking as follows:

“I might need a little more time to think about the thought in order to get it out of my mouth and it might go a little slower than it does for non-spastic persons. So I will lag behind...It depends on the circumstances. It is not so much when I am at home, but if there are distractions around me, which I can't tune out, then I have difficulties keeping my concentration and saying what I want. And it's annoying sometimes because your message doesn't come through, even if you have one, and you will sometimes be perceived as stupid. I find very often that I become passive in those conversations and that makes me sad.”

JO, without CP, acknowledges that we all communicate in different ways:

“One aspect is our speech and when it's not quite as you would expect from people, then you have an instant impression. The second aspect is that, if your body language doesn't match, then you have two parts of your communication already ruined.”

“[Communicating with persons with CP] will be something that takes up a lot of the concentration you have. You get sidetracked when something happens all the time in one's field of vision. Everybody knows that. If we talk to children where it's full speed ahead, that's rough. You have the same if people have uncontrolled movements, because is it a part of the speech or is it an uncontrolled movement? You first of all have to include that in your decoder.”

Due to the different way of communicating in CP, the persons without CP typically misunderstand the situation and it's very common that this leads to action failures HJ, with CP, who doesn't have a speech impediment, describes a specific example of getting out of a bus:

"Usually they ask 'Do you need help', and before they have finished asking, they have grabbed the arm or something else. I look him in the eye and say 'No, thank you, I can do it myself', and so he begins to pull me out of the bus. So I look at him and say, 'I can do it myself.' He doesn't hear me. He just pulls me out of the bus. Then afterwards you stand there a little flustered."

Communication difficulties are described by all the participants with CP, both with and without a speech impediment, as one of the crucial difficulties for their social engagement. However, the communication difficulties persons with CP have are interrelated to the uncertainty that persons without CP experience. PW, a 42-year-old woman without CP, relates the experience of uncertainty to that of embarrassment in communicating with a person with CP:

"It's more about if you aren't able to understand, if you repeatedly have to ask him, then you become embarrassed. It's simply not good enough that you can't understand what he says and you will feel a little embarrassed, because it's rude not to be able to understand what he says."

Thus, there is more to communication than having for example the motoric and cognitive abilities to speak. It takes two to tango, and an uncertain situation will only make the communicative dance more difficult.

Another aspect of uncertain in communicating with a person with CP is that of joining attention, since, as FN, with CP, says

"I have a brain damage where my eyes, especially when I'm tired, are just all over the place, and I squint a little to one or the other side. Many have actually asked me if they can help me across the road or whether I was blind and if I could see something."

AL, without CP, relates the attention difficulties of engaging with disabled persons to her experience of uncertainty:

"You have been taught that you shouldn't look at disabled persons, not look at people in wheelchairs. But if you need to talk to [someone who is disabled], where should I look? A tiny thing: if people are cross-eyed, then I have no idea where I should look. I take myself to look down and that's also wrong."

### 4.3. From Failure to Success

We see that, in engaging with CP, there are substantial communication difficulties, which makes it problematic to understand how to engage with the other stranger. Persons without CP typically misunderstand the situation and the behavior of the person with CP. DM, with CP, describes such misunderstanding in the following example:

“I’m walking up the stairs, and there is a railing on one side, and I take a hold, and it may well be that I just need to concentrate a little to get my leg up, but then there is already someone who grabs me and says ‘I’ll help.’ Well I don’t need your help, I can do it. It may well be that it doesn’t look so cool, it may also well be that it takes longer, but I can...I have learned to figure out those methods, so that it works. It may well be that it’s not pretty, it may well be it is more time consuming, but it functions.”

DM experiences being in control of the situation and her overall aim is to walk up the stairs herself. Persons without CP, however, misunderstand her behavior and the situation as being uncontrolled, uncertain and potentially dangerous, and they try to help her. NJ, a 25-year-old man with spastic tetraplegia, believes that persons without CP try to help, because they see him as unpredictable and this leads to an experience of uncertainty in them:

“They are uncertain of what I am and I believe they think I’m unpredictable. And if there is something people don’t like, then it is unpredictable people or things. People just don’t like that. And therefore I also become aware of it and again this filter arises where I begin to reflect on what they believe and think.”

NJ describes that, when he then experiences the uncertainty of persons without CP, it increases his self-awareness, and he starts to reflect on how they experience the situation. The uncertainty of the situation creates a kind of reflective spiral, which is described by the participants, both with and without CP, as characteristic for engaging with CP. Primarily due to the experience of uncertainty, both strangers significantly reflect on their own behavior, on the other persons and on the situation. This reflective strategy usually leads to more reflection and in the end to misinterpretations of the other person and then to action failures.

In the main part of the interview the participants describe the difficulties of engagement, highlighting experience of uncertainty and action failure. However, the participants, both with and without CP, also describe aspects of engagement that relate to action successes. AL, without CP, describes that in the encounter “we need to agree that we both are totally awkward about this situation and then just try to get the best out of it. It can’t be any worse than if you just avoid the problem.” TN, a 38-year-old man and spastic hemiplegic, says that “you are in a situation where you just need to collaborate about something in order to

achieve a common goal, and if you are not ready or willing to collaborate about it, then it all goes wrong.” The way in which this collaboration is described is typically when the persons without CP start to communicate their uncertainty in the encounter. They do so by gesturing uncertainty or verbally questioning their own actions and engagement. AL, without CP, says that:

“I’m not able to put myself in their position, so I don’t know how to behave in this different encounter...How do you do this best for them? You just need to ask them. They might just be as uncertain about it as you are.”

Asking the person with CP for guidance is described as a way for the persons without CP to communicate their uncertainty, but the situation is a bit more complex, as TV, a 28-year-old man with spastic paraplegia, explains:

“It’s not good to be a wallflower, because you must have some idea that people want to help you, which they will of course, but how will people know how, when and why they should help you, if you don’t even open your mouth and say that I would like some help. To put things the other way around, you should also push yourself and say if I can perhaps do something myself, then I will do it myself...Eventually I had to learn that first of all, they are strangers, they don’t know you, so you can just smile, even if they pick up your crutch, when you can do that yourself.”

What TV problematizes is that there is a fine line between being helped by and collaborating with the other person. In the latter situation, TV continuously performs the actions he is able to do himself. AL, without CP, acknowledges this fact and describes that in actually helping the person without CP it’s important

“to attend more to how they react to [the encounter], how they respond to me. All the time it has been way too much about me, that I almost become completely beside myself when I have to face someone who acts different from me.”

For LA, a 40-year old man without CP, “it’s about attending less to the disability and less to the challenges, and more to the person. It’s a little cliché...but it changes your entire web of engagement with the person.” When he is met by such an attitude HJ, with CP, describes that he experiences what he calls an ‘unreserved openness’:

“I experience a great kindness that is an unreserved openness, where people very quickly read the situation. Sometimes they may be uncertain about what to do, but then people are extremely polite to ask ‘what should I do’, then you say this and this and that, and then they do it.”

Many of the participants with CP describe that this attitude gives them an experience of control in the engagement with the strangers. For example, MA with CP describes, as follows, the situation of being met with such attitude while eating at a restaurant:

“It means that I can relax more and then the situation becomes less convulsing. I don’t use as much energy...It’s in relation to my spasms. When I can relax more, I can better control the fork and those kinds of things.”

## 5. Discussion

As described in the interviews both participants with and without CP find the situation uncertain, and they need to engage with one another in order to perform the action successfully. This kind of social situation doesn’t only arise in the context of engaging with CP of course. In helping, for example, a stranger, or even a friend, move her heavy couch up a narrow staircase, experiences of uncertainty may arise: uncertainties in the best way of performing the action or carrying the couch, for example, or in the ability of both the person at the top of the stairs to hold on to the couch and the one at the bottom to keep up with the pace of the person in charge.

Communication is a crucial factor in dealing with the experience of uncertainty. In the descriptions of action failures above, the participants with and without CP fail to communicate, in figuring out how to best help the persons with CP. As highlighted by Peckitt et al. (2013), the communicative difficulties in CP can be compared to stuttering, where the disorder is far more than speech disfluency and disruption. It relates to other auxiliary features such as anxiety, worry, guilt, or shame (Williams 2006, 2), which in this case of engaging with a stranger increases the experience of uncertainty. Nevertheless, the persons need to communicate, so that they, despite the uncertain nature of the situation, achieve a common goal.

These communicative difficulties are not something that only arises in relation to persons that stutter or have CP. Another example is trying to get a conversation going on a blind date. Because they are strangers and are on a first date, both persons are nervous and might be extremely self-conscious, constantly reflecting on how to ask and answer questions. In some cases, this might lead to an increased experience of uncertainty and to communicative difficulties, in which the persons interrupt each other or moments of awkward silence occur.<sup>47</sup>

How should we understand the successful act of helping in the case of CP, when taking these aspects of uncertainty and communication difficulty into account?

### 5.1 Sharing in the case of CP

In the above definition of cooperation, it’s seen as necessary that one should be able to infer the intentions of the other in order to merge them with one’s own intentions into one common goal. In other words, t’s necessary that the intentions can be, in some way, shared, so that one is able to make predictions about the

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<sup>47</sup> Thanks to Olle Blomberg for pointing out the more common nature of the communicative difficulties in CP and suggesting the example of a blind date.

intentions of others to achieve that same goal. However, as emphasized in the case of CP, persons without CP typically misinterpret the situation, the behavior of the person with CP and it's very common that this leads to action failures. Persons without CP describe that it's difficult for them to put themselves in the shoes of persons with CP, because living with CP seems to be so different from their own lives. In addition, persons with CP also describe difficulty of understanding the person without CP, and due to the experience of uncertainty, both strangers significantly reflect on their own behavior, on the other person and on the situation. The uncertainty of the situation creates a reflective spiral, which leads to further misinterpretations and ultimately to action failures.

It seems that in the case of CP the two strangers are not directly able to understand one another's intentions and so the successful cases of helping wouldn't be one of cooperation, as it is defined by Warneken and Tomasello (2007). There might be different reasons for this, but, since spastic CP is a brain damage in the motor cortex, one reason might be neurological and related to the so-called 'mirror neurons'. Based on studies on macaque monkeys (di Pellegrino et al. 1992; Gallese et al. 1996; Rizzolatti et al. 1996), it was proposed that, when humans observe an action, our motor system becomes active in simulating the action observed, as if we were ourselves executing that movement. Our ability to understand the intentional actions of others rely on these mirror neurons, which supposedly is located in the par opercularis of the posterior inferior frontal gyrus (Brodmann area 44), the human equivalent of monkey area F5, and in the rostral inferior parietal lobule (IPL), the human equivalent of area PF/PFG (Rizzolatti et al. 2001; Rizzolatti 2005; Rizzolatti & Craighero 2004; Iacoboni & Dapretto 2006). In order for the observer to translate the observed movement into something understandable, the action of the other needs to match one's own motor repertoire. One understands the action of the other, because one can perform the action oneself (Gallese 2001; Gallese & Sinigaglia 2011).

In such explanation of mirror neurons the activation of the neurons doesn't seem possible in the engagement between persons with and without CP, since their motor repertoire is so very different from one another. Additionally, the brain lesion in CP is typically located around the primary motor cortex (M1), and can therefore include direct lesions of the posterior inferior frontal gyrus and the rostral inferior parietal lobule, or indirectly affect the areas by disrupting a functional network between the M1 and the areas. So, how are we to understand why successful actions while engaging with CP are still possible.

This is because the successful engagement in this case of CP is not that of cooperation, but of collaboration. As mentioned, engagement should be understood in experiential, affective and emotional terms, and not neurological or mental terms. Merleau-Ponty, for example, has described communicative engagement as "a shared operation of which neither of us is the creator...we are collaborators for each other in consummate reciprocity. Our perspectives merge into each other, and we co-exist through a common

world” (Merleau-Ponty 1962, 413). This quote highlights the different notions and aspect that should be the focus in understanding engagement, namely collaboration, reciprocity, we-perspective and a common world.

Roschelle and Teasley (1995) defined collaboration in terms of a Joint Problem Space (JPS), which is negotiable and shared conceptual space constructed through a shared language, situation and activity. The focus on concepts and the use of language is problematic in our case of CP, since, as we have already seen, communication, verbal or not, is difficult in engaging with CP. However, in contrast to the acts of cooperation, Roschelle and Teasley emphasize sharing a situation, a space and a problem. In the engagement with CP, the persons with and without CP share a situation they both experience as uncertain and problematic.

As we have seen, coordinating and correlating movements and actions in the situation are problematic for both person with and without CP. This means that in order to understand the successful actions, we can't describe the success in terms of coordination and correlation of the movements and actions. Zahavi has recently given a phenomenological and second-person perspective on the notion of 'emotional sharing' by saying that: "Perhaps the most unique feature of the second-person perspective isn't the action part, isn't the fact that one is aware of others' mental states as a result of engaging and interacting with them, but is rather the issue of reciprocity (de Bruin et al 2012, Fuchs 2013)" (Zahavi 2015, 12). Although Zahavi use the notions of 'engagement' and 'interaction' interchangeable he doesn't, as Fantasia et al. (2014), describe the second-person perspective in terms of interaction, but instead in terms of 'reciprocity'.

Zahavi describes the notion of 'reciprocity' further by appealing to the we-experience we have when engaging (Zahavi 2015, 95). When we seek to influence others, and the other is aware that he is being addressed and reciprocates, and when both of us are aware that we are experienced and understood by the other, we engage in communicative acts through which a we is established. Through these communicative acts and an accompanying we-experience the world acquires the character of a truly social world (Husserl, 1973, 472; 1952, 192-4). In the case of CP this means that when both person with and without CP become aware that they are experienced and understood by the other, a we-experience for dealing with the uncertain situation is established. This we-experience becomes the point of departure for the collaborative engagement, but as both Zahavi and Satne and Roepstorff (2015) argue, this reciprocal we-experience only occurs when we experience the other as a 'you', as a person.

## 5.2. Trust: Committing to the Engagement

As mentioned in the beginning of the paper, Satne and Ropstorff describe the normative aspect of engagement by highlighting a relation of mutual and interpersonal commitments in the engagement (Satne & Ropstorff 2015, 20). They define this commitment in terms of responding and tailoring the engagement in relation to the *expectations* of the other person. Interrelation of expectations shouldn't be understood as



guessing what the other person is expected to do, but as a commitment to tailor the engagement according to future normativity, i.e. expected patterns of actions and reactions. I agree with the attempt to describe engagement as extending beyond the here and now of the actual interaction, but in the case of engaging with CP, using the notion of 'expectation' to understand the normative aspect is problematic. In this case it's difficult to rely on expected patterns of actions and reactions, since CP, being a motor control disorder, makes the experience of engagement unpredictable and uncertain.

However, as described by both participants with and without CP, when they experience and agree that they are both sharing an uncertain situation collaborative engagement seems possible. Such we-experience doesn't arise due to the acquiring of knowledge of the other persons predefined intentions, motives or goals. The persons with and without CP are not able to communicate and thereby to acquire knowledge of each other's intentions, and that is partly the reason why the situation is experienced as uncertain. The notion of 'trust' is seen in the literature as fundamental for handling uncertain situations (Becker 1996), as well as for communication (Luhmann 1990; Liebsch 2010), for experiencing and recognizing others as persons (Jones 1996; Bernstein 2012) and for cooperation/collaboration (Baier 1986; Luhmann 1990). The notion therefore seems fundamental for understanding how the persons with and without CP commit to the engagement in order to successfully help the person with CP.

Trust is typically described as involving two components: 1) one which is cognitive and strategic and includes beliefs about the trustworthiness of the other, and 2) the other which is emotional and motivational, and comprises an attitude towards the trusted person and the world (Becker 1996; Jones 1996). I'll adopt a broad and pragmatic understanding of trust that includes both components. Although their relation is much more complex and intertwined, I'll present them as somewhat separate in order to clarify what trust means in this case of CP.

If we start by looking at the cognitive and strategic component of trust, it has been argued that trust is a way to manage uncertainty (Becker 1996, 45). This uncertainty arises, because we lack either sufficient knowledge to understand the other or to understand the situation. We are therefore both insecure (Becker 1996) and vulnerable (Baier 1986) but, as Baier highlights, trust is precisely the acceptance of this vulnerability (Baier 1986, 235). As describe in the interviews, collaborative engagement requires that both strangers accept that they are sharing an uncertain situation.

This acceptance of sharing an uncertain situation typically arises when the persons without CP communicate their uncertainty in the encounter. They do so by gesturing uncertainty, by verbally questioning their own actions, and by asking the person with CP for guidance. Doing so is not meant to obtain knowledge of the intentions of the persons with CP, but is a way to share one's uncertainty and to create trust in the engagement. Jones describes such strategies as a way to cultivate trust, whereby it's possible to bootstrap our patterns of attention, our lines of inquiry, and our interpretations of the other person (Jones 1996, 22). Using

such strategies to bootstrap trust and manage uncertainty does not always lead to the actual experience of trusting the other. It does, however, illustrate a way to approach the person with CP that increases the chances for successful collaboration. This means, for example, that, if the person with CP says that the person without CP is holding their arm too hard, they trust the person with CP enough to change their own actions.

However, trust is “not only a way of handling uncertainty; it is also a way of being, a way of going, in uncertain or certain terrain. It is one of many possible general structures of concrete motivation, attitude, affect, and emotion” (Becker 1996, 50). Trust can also be understood as an emotion or attitude, which motivates and structures the way in which we experience a situation and attend to the other (Jones 1996, 11). Thus, in sharing an uncertain situation trust is a way for the strangers to be mutually motivated to develop a common goal of how to help the person with CP. This goal is developed during the engagement and throughout the uncertain situation. Collaboration in the case of helping the person with CP can therefore be understood as a kind of phenomenon where a common goal of *how* to help emerges and develops through the trusting engagement.

One way to describe how this happens, as it’s also mentioned in the interviews, is when there is a shift of attention from oneself to the other, and where this is a trusting attitude in which we recognize the other as a person, who reciprocally recognizes us as a person (Bernstein 2012, 402). Recognizing and attending to someone as a person means upholding their autonomy and self-control. In other words, trust becomes a question of actually abandoning control of the actions performed by the other. Of particular interest for the case of engaging with CP, given that it is a motor control disorder, is the fact that, when both persons trust in the reciprocity of one another and abandon the attempt to take control over one another, it actually gives both a sense of control (Becker 1996, 58).

The participants with CP describe the sense of control in different ways in the interview. One participant uses the notion of ‘openness,’ which means that when both strangers come to feel in control of the situation, they shift the focus of their intentional attention from themselves to their action possibilities. We feel in control in collaborative engagement not by exerting control over the other, but by letting the world reveal our possibilities of action and acting in accordance to them. These action possibilities are of course different for the person with and the person without CP but, when this shift of attention happens, they both continuously attempt to negotiate their engagement and actions in order to successfully reach their common goal of helping the person with CP.

Action difficulties and failures are always possible, and also happen in many of the successful cases of engaging with CP. Nevertheless, when both persons experience a feeling of control in their engagement, they act in a way that, despite uncertain factors, shows them the possible actions they are able to take, even when

action failures occur. Borrowing the Husserlian notion of ‘I can’ (Husserl 1960, 45, see also Husserl 1989, 270-271), this reciprocal we-experience of trusting each other could be described as a ‘we can’.

The overall point is that successful collaborative engagement is not a question of knowing intentions and avoiding action failures. Trust is an attitude that actually allows for risky decisions without sufficient knowledge and for action failures (Luhmann 1990, 100 and 103). It is an attitude of recognizing the other as a person and being recognized by the other as a person, so as to share an uncertain situation together. When this happens, as one participant with CP describes, the experience of uncertainty disappears and she relaxes, which means her spasms decrease and she experiences being more in control. As one participant without CP describes, this attitude of being recognized as a person changes your entire web of engagement with the person. For both persons with and without CP the trusting attitude becomes a motivation for collaborating through the entire engagement, until the common goal of helping the person with CP has been achieved. Collaboration is therefore to be understood as process of trusting commitment where ‘we share’, ‘we risk’, ‘we fail’, but ‘we can.’

## 6. Conclusion

In this paper, I have tried to understand how the engagement between two strangers unfolds in order to help the one with CP. I have described this engagement as one of collaboration, where knowledge of the other’s intentions isn’t necessary, since trust is a sufficient component for success. This description shouldn’t only be seen as relevant for this case of engaging with CP but also, more generally speaking, for how to understand the act of collaboration, where communication difficulties, uncertain situations, risky decisions and control issues are a constant problem. The description is also relevant for much professional and therapeutic work with CP, where there is this fine and complex line of figuring out when the act of helping counterproductively leads to action failures and how to collaborate in the engagement with CP.

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## Part III

# Relevance: Collaboration, Communication and Cultivation

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## Chapter 8

### 'Yes We Can': Embodied Cognitive Intervention for Cerebral Palsy

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# 'Yes We Can': Embodied Cognitive Intervention for Cerebral Palsy

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## Abstract

During the last decades, research on cognition has undergone a reformation, which is necessary to take into account when evaluating Cognitive Behavior Therapy (CBT). This reformation is due to the research program called Embodied Cognition (EC). Although EC may have become the theoretical authority in current cognitive science, there are no established EC based framework for therapy. For developing such framework, CBT becomes relevant, since it already has a well-established framework and the current third wave of CBT emphasizes like EC the contextual, experiential and active aspects of cognition and behavior. Thus, there might be a possible opening for cross-fertilization between the two. In this paper an EC based model of intervention for working with self-control in cerebral palsy (CP) is presented in order to further develop a framework for EC based therapy and discuss the possible collaboration with the third wave of CBT.

Key words: embodied cognition, cognitive behavior therapy, cerebral palsy, self-control, pre-reflective experience, enacted bodily activities, social engagement.

## 1. Introduction: Embodying Cognitive Therapy

During the last decades, research on cognition has undergone a reformation, which is necessary to take into account when discussing the relation between cognition and behavior, and when evaluating Cognitive Behavior Therapy (CBT) in relation to other current therapeutic proposals. This reformation is due to the research program called *Embodied, Embedded, Enacted and Extended Cognition (EC)*.<sup>48</sup>

As a point of departure, EC criticizes, and is an alternative to, traditional cognitive science. The latter goes by different names, but is often called cognitivism, and is criticized for reading cognition in mental terms and situating it within the skull. In contrast, EC holds different fundamental claims, which stress that cognition is not only skull-bound, but is something experiential and emotional that we enact in the world, together with others and through the use of technology (Varela et al. 1991; Clark 1997; Wilson 2002; Noë 2004; Thompson 2007, 2014; Gallagher 2005; Gallagher & Zahavi 2008; Chemero 2009; Rowlands 2010).

This embodied reformation of cognitive science illustrates a close relation between cognition and behavior, but isn't therefore a return to behaviorism. The relation should be understood in neither physically

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<sup>48</sup> We will use the term Embodied Cognition (EC) as a broad term that encompasses the other E-aspects.

reductive nor mentalistic terms, as Merleau-Ponty, one of the fathers of EC, argues: “behavior is not a thing, but neither is it an idea” (Merleau-Ponty 1967, 127, see also Merleau-Ponty 1962, 126-27). Instead, cognition and behavior are related through our embodiment, which should be understood as the (en)active and situated nature of our bodily experiences.

The aim of the present paper is not to go into a theoretical description and discussion of EC in relation to behaviorism and cognitivism, as this has already been done thoroughly by Merleau-Ponty and many of the other EC theorists. The aim here is therapeutic: although EC may have become the theoretical authority in current cognitive science, there are only sporadic examples of EC based therapy, and no established framework.<sup>49</sup> The overall aim is therefore to further develop such an EC framework of therapy.

For such a task, CBT becomes relevant, since it already has a well-established framework for cognitive and behavior related therapy; so, instead of ‘reinventing the wheel,’ CBT could be a source of inspiration for further development of EC based therapy. One way to characterize the framework of CBT is by distinguishing between three different waves (Hayes 2004). The first wave was a behavioral and empirical based opposition to the humanistic concepts seen in for instance psychoanalysis. The second wave introduced cognitive aspects to behavioral therapy, but was highly influenced by the cognitivist tradition, appealing to the internal machinery of cognitive events and processes. EC criticizes both behaviorism and cognitivism, which these two waves are based upon, so the source of inspiration would be very limited.

The aim, methods and techniques of the current third wave of CBT, also called contextual methods of CBT (Hayes et al. 2011), have different purposes and assumptions than the previous two waves of CBT. Like EC, they emphasize the contextual, experiential and active aspects of cognition and behavior. Thus, there might be a possible opening for cross-fertilization between EC and the third wave of CBT. The questions are then: how does EC-based therapy relate to third wave CBT, and what are the possibilities for collaboration between the two?

## 2. Developing EC Therapy for Cerebral Palsy

In order to try to answer these questions we will look at the case of cerebral palsy (CP), in which one fundamental issue is that of *self-control*. This case is interesting, since the issue of self-control is important for discussions in both CBT and EC. We will present a pilot-study of an EC based model of intervention for working with CP and center the results of the study and its discussion on how we should understand and work with self-control in therapy.

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<sup>49</sup> We will present examples of EC based therapy in part 5 Discussion: Self-control in CP.

## 2.1 Cerebral Palsy and Treatment Protocols

As an umbrella term, CP is defined as a group of disorders affecting the development of postural and motor control, occurring as a result of a non-progressive lesion in the developing central nervous system (Bax et al. 2005). In 90 % of the cases, the lesion occurs during pregnancy (Ellenberg & Nelson 2013), making CP the most common type of disorder associated with lifelong motor impairment (Aisen et al. 2011). At the same time, CP is a heterogeneous condition that varies according to the particular brain lesion and individual in question. As a result, CP is typically classified according to its different types of motor symptoms (spastic, dyskinetic, or ataxic) and to the bodily location of the motor impairment (mono-, hemi-, para-, and tetraplegia).

Spasticity is seen in most cases of CP, where the lesion affects the upper motor neurons, damaging the motor neurons' ability to regulate descending motor pathways, which results in muscular overactivity (e.g. exaggerated tendon reflexes and hypertonia) (Dietz & Sinkjaer 2007; Sheean & McGuire 2009). Thus, the current research and clinical focus for CP is invested in developing and optimizing antispasticity treatment protocols (Pandyan et al. 2005). These protocols work on the assumption that there is an implicit, yet unproven, causal relationship between the neuro-physiological disorder (spasticity) and behavior, i.e. activity limitations, participation restrictions and reduced personal independence (Barnes 2001). Despite extensive work on these neuro-physiological aspects, the clinical impact on such behavior is still limited (Sheean 2001, Pandyan et al. 2005).

Only a few studies have discussed the cognitive, emotional and social implications of living with CP, such as increased barriers and problems in social participation and peer relations for children with CP (Imms 2008; Bottcher 2010), or struggles in coping with a negative body image for adolescents with CP (Hammar et al. 2009). Research that focuses on the experiential as well as the cognitive and social aspects of living with CP as an adult is more or less non-existent (for one exception see Peckitt et al. 2013).

Recently, Martiny (forthcoming, see also 2015)<sup>50</sup> has presented first-person descriptions from adults with CP (ages 22-58) that highlight the feeling of uncertainty they experience in performing many of their daily actions. The experience of uncertainty may lead to the disbelief in one's own abilities, self-doubt, and the use of maladaptive control strategies such as extensive planning, worrying, and bodily monitoring. These strategies typically lead to mental exhaustion and limited physical activity and social participation.

We suggest that, in order to work with the behavioral aspects of CP, such as activity, participation and independence, we also need to focus on its cognitive, experiential and social implications, such as those highlighted above. Together with the Helene Elsass Center (HEC), a center working with the habilitation of persons with CP, we therefore developed an EC based model of intervention by means of which to do so.

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<sup>50</sup> See chapter 4 and 6 in this Ph.D. dissertation.

## 2.2 Winter Camp

This EC based model of intervention consisted in a 5-day winter camp in Beitostølen, Norway that the HEC arranged in the spring of 2014 (March 5-9). There were 11 participants, 4 girls and 7 boys, between the ages of 14 and 18, who were all diagnosed with spastic CP and whose motor function correlated to Level I-II of the gross motor function classification system (GMFCS) developed for children with CP (Palisano et al. 1997). While the criteria for selection did not require that the participants already were able to ski (of the 11, only 5 had tried it once before), they were expected to have independent gait function and to be able to manage their own personal care.

The overall question of the pilot study was: *will a model of intervention working with embodied aspects produce behavioral effects?*

## 3. Design and Method

The camp was structured as a group activity in which the participants would be confronted with challenging and physical activities that they wouldn't dare take on in daily situations. The primary activity was centered on skiing, a physical activity that is experienced as very uncertain and challenging for people with CP. Skiing requires specific motor skills and balance, which is problematic for persons with CP. In addition to skiing, there were also other activities such as snow rafting, dog sledding and indoor social activities, which had the same purpose of challenging the participants. The overall aim of these activities was not to learn to ski, snow raft or dog sledd per se, but rather to create an embodied experience of overcoming challenges.

### 3.1. Structuring the Challenging Activities

The difficulty was to structure a social environment so that the participants would be encouraged to take up the challenges. This was done by a professional team of two ski instructors and 4 staff members from HEC, one of whom has CP. All of the staff members have professional experience working with CP, and their knowledge basis spreads across different disciplines such as physiotherapy, psychology, occupational therapy, sports physiology, pedagogy and educational sociology.

The team worked with a number of different physical, cognitive and social strategies to encourage the participants to take up the challenges:

- 1) The team designed a 3-week pre-defined physical training program that participants were supposed to follow before the camp in order to strengthen their muscles and balance.

2) Throughout the time at the camp, the team continuously structured the challenges together with the individual participants and according to their particular preconditions, expectations, goals and level of function.

3) The winter camp included meetings where the team and all the participants met together. These meetings were designed to promote a social structure among the participants that would strengthen the group, and were scheduled to happen a) one time before the trip, b) at the airport before departure, c) every morning and evening at the actual camp and d) at the airport upon returning from the camp.

4) The purpose of the large meetings was also to give the participants individual coping strategies they could use to deal with challenging situations. For example:

4a) The participants were told to verbalize their experience if they felt uncertain, out of control, or stressed. For instance, the participants could talk to their own bodies in order to gain control, e.g. “stop that, I’m in charge”, or they could describe the experience of an uncertain situation, e.g. “I’m ok, only 20 meters more, and then I can stop.”

4b) The participants were also given a color narrative with which to describe their experience of undergoing a challenging activity. If the activity wasn’t challenging enough, they described their experience as being in the “green zone”. If the activity was challenging them, but they experienced the possibility of overcoming the challenge, they described it as being in the “yellow zone”. If the challenge was too extreme or overwhelming, and the participants were panicking, they described their experience as being in the “red zone”.

4c) The participants were also asked to describe their expectations and evaluate their own performance in positive terms. This meant shifting their attention from many of the failures that they expected to, and did experience to the experiences they hoped to, and actually did, succeed in doing. This was done in the group meetings, where, every morning, they described a positive expectation for the day and, every evening, positively evaluated their experience of the day.

### 3.2 Method: Phenomenological Interview

We used qualitative interview to assess the experiences and behavioral effects of the winter camp. Acquiring clear and accurate descriptions of a person’s experiences is a science in and of itself. Within EC, the *Explicitation Interview*, a second-person semi-structured interview method with its own specific questioning and analysis techniques, is an example of the attempt to develop such a science of experience (Vermersch 1999, 2009; Petitmengin-Peugeot 1999; Petitmengin 2006; Petitmengin & Bitbol 2009; Bitbol & Petitmengin 2013).

This interview method uses open ‘how’ questions and specific questioning strategies to draw the attention of interviewees to detailed aspects of their experience, thereby making them able to give detailed first-person

descriptions of their lived experiences. In our case, the focus was on how the participants experienced themselves and their own bodies while going through challenging activities during and after the winter camp. The interview methodology won't be further described here, but a full account of the methodological considerations and how they relate to EC can be found in Høffding and Martiny (forthcoming).<sup>51</sup>

We used the interview method to understand the participants' experiences at 3 different times: 1) a week before the winter camp, 2) a week after the winter camp, and 3) two months after the winter camp. The 11 participants were divided into three groups, one with 3 persons and two with 4 persons. This was done primarily for pragmatic reasons, since the group with 3 persons lived in Jutland, and it was thus easier to meet with them together.

The specific interviews (3 x 3, 9 in total) took around 1-1½ hours, and the descriptions elicited from the 9 interviews were structured and analyzed in accordance with phenomenological methods of descriptive analysis (see Gallagher & Zahavi 2008, chapter 2). Since this study is a pilot, we didn't operate with a control group, but used the strategy of "phenomenological consistency" in order to validate the descriptions and evaluate them in relation to the behavioral effects of the intervention (see Høffding and Martiny forthcoming).<sup>52</sup> Phenomenological consistency involves both internal and external aspects of analysis, where internal phenomenological consistency refers to the ability to make comprehensible all the participants' different descriptions found in the interview. The more descriptions a certain phenomenological interpretation can make comprehensible, the deeper the internal phenomenological consistency. External phenomenological consistency refers to the ability of the overall account produced to work with and against already established theories of the phenomena in question. External phenomenological consistency is related to the methodological step of "intersubjective validation" (Varela & Shear 1999, 10) or "intersubjective corroboration" (Gallagher & Zahavi 2008, 29-31).

Two participants were unable to make it to the third and last interview round, and the names of all the participants have been anonymized in the following results.

## 4. Results: Experiences of Control

This section will present the results of the interview by focusing on the experience of control as a way of understanding the participants' development during the winter camp and what this meant for their daily life after the camp.

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<sup>51</sup> See chapter 3 in this Ph.D. dissertation.

<sup>52</sup> See chapter 3 in this Ph.D. dissertation.

## 4.1 From Executive to Embodied Control

Being asked about the upcoming winter camp in the first interview round produced great excitement for all the participants, but also experiences of nervousness and uncertainty: ‘what if I cannot walk in the ski boots?’, ‘what if I fall and hurt myself?’, ‘what if it’s too challenging?’, ‘what will the other participants think of me?’, etc. Such worrying and questioning were characteristic for both those participants that had skied before and those that hadn’t.

In order to deal with such experiences of uncertainty and worrying, the team had, as mentioned, given the participants different physical and cognitive strategies to work with prior to the winter camp. However, when the participants got on the skis, it was necessary for them to learn to keep their balance and be able to perform some basic movements. Such as those required in breaking or stopping, both of which beginners primarily accomplish by so-called ploughing. Being able to plough gave the participants an experience of control over the current situation, so they could take on new challenges. Søren describes it as follows:

“It was great to learn to plough, since then you could accelerate, but before that, you could only take the small hills where you didn’t get much speed. When you could plough, then you could take the big ones... It was liberating. [I: Were you sometimes uncertain?] Sometimes I was, but not very often. Then I just sat down and gained control. It was great when you got down to the bottom of the hill and then looked up: ‘I’ve just run down that.’”<sup>53</sup>

Søren’s description is one example of how to acquire control in an uncertain situation by either ploughing or sitting down. This requires that the participants are attentively aware of and control their bodily movements in such a way that is very cognitively demanding. Another example of this type of control is how the participants talk to their bodies in order to gain control over them. Signe gives the following description:

“Many times I also spoke to my legs, because my legs don’t really want to do what I want. So, there were times where I told them ‘now you will stop, now it’s me who decides’ and then we went down the piste again...My legs said that they couldn’t anymore, they did not want to be there anymore, but my head said something else. I think it’s a way to gain control. Often I said ‘right, right, right, right’ or ‘plough, plough, plough, plough, plough.’ Many times, I said that to myself, and I think that when you say it out loud, it helps your body to obey...It wasn’t always that [my legs] would obey.”

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<sup>53</sup> In this and the following quotes, ‘I’ refers to the interviewer.

Signe's description is characteristic for all the participants and illustrates the tension in CP between the cognitive and bodily aspects of action. The participants want and intend to perform a particular action but, due to their motor control disorder, they aren't always able to do so.

After having skied for a couple of days and learned many of the basic movements, the participants describe a different kind of control than that experienced in having to acquire control. Ditte describes it as follows:

"One thing is to ski down a hill, but it's something else not to feel insanely scared when going down the hill, [to feel] that you are able to enjoy it when skiing down the hill, so that one's thoughts are not only focused on 'how do I stop, how do I stop, how do I stop,' but that there is also time to see where I'm skiing, who I'm skiing with, what they are doing, or how it looks where I'm skiing. I think it's also great that you can concentrate on the fact that you can have this surplus...that you feel that it doesn't constantly turn into: 'oh no, oh no, oh no, oh no, how should I do this?'...It's nice to be able to do something, but it's also nice to feel that you can really do it and that it's not just skiing down the hill and then sitting down in order to stop. But it's skiing down the hill, trying something new, looking around...the feeling that I can easily ski and then at the same time, without being worried, keep an eye on Jeppe [another participant], that too was nice. The freedom that I can look at him and that I don't always have to focus on my ski, focus on not falling or on loose snow, or something like that.

Ditte's description highlights that there is a different way of experiencing being in control, where the participants don't need to be aware of their bodies or the skis in order to be able to plough or stop. Instead, this is an experience where the participants feel that they are able to perform what they intend to perform, where they have the capacity to experience the environment and people surrounding them, and where they are not afraid, but feel free and enjoy the experience of skiing.

In this experience of being in control, the participants focus on their surroundings, let their movements and actions depend on what's going on around them, and are relaxed and calm in their actions, despite unexpected things happening. This gives the participants the motivation and courage to make decisions and to act in ways that might be uncertain and unpredictable. Jeppe provides a description of skiing off-piste with another participant Benjamin in the forest:

"Sometimes, you couldn't stop. I drove right past [Benjamin] at one time and that wasn't on purpose, but there was just a place where you got a lot of speed and I couldn't stop, so I fell...[I: Do you like losing control?] No, no, it wasn't to lose control as such. It was just fun and it was to be challenged."



This experience of being in control, without having to acquire control, gave the participants a belief in their own abilities and motivated them to take on more and more challenging activities. Rasmus describes his development in the following way:

“The last day of skiing was the strongest experience, one might say. It was really, really awesome, because there you had to prove or show what you had learned during these days...We tried and we just threw ourselves into it. I hadn’t tried to ski on the red piste at that time, but I stood there and looked down at it, and then I just did it. You just do it fearlessly...It doesn’t matter if you fall...It was like we were able to ski more all-round...You had control of everything. I could see a difference from day one to here, where I just felt that ‘I’m ready for [the] X-Games’”.

## 4.2 Sharing Control

The participants describe that one of the main reasons why their experience of control developed during the winter-camp was the social structure of the camp. The professional team and the participants themselves provided the necessary guidance and collaboration for the individual participant to overcome the challenging activities. Ditte describes how both the team and the other participants helped and motivated her to ski down a challenging hill:

“It was her, [the] coach I had, she was also really cool...She cheered on our behalf, and it was just great that there was such cheering...In the group I was skiing with, whenever a person did something the person really wanted to, everyone was there and there was cheering among everyone...You did it together. We were all in this together.”

Ditte highlights that it’s the sharing of the challenging activity together with others that makes a fundamental difference. They are cheering each other on and, when they fall, they don’t experience it as a failure or as being ridiculed by the others. They are all part of a group where everyone falls and they laugh about it together.

Sharing an uncertain situation with someone from the professional team makes the participants more relaxed, which gives them control over the situation. Signe describes how she is guided through a ‘red zone’ experience as follows:

“We had to go all the way down from the top, but [someone from the staff] was there just for me, and to make sure that I was calm, because I was in the red zone. There was really a long way down...I don’t know how I would have come down by myself. So, it was good that I had [the staff member] to help me and support me. [I:

Did that help you out of the red zone?] Yes, it did. I was still close to it, but I wasn't all the way up in the red zone, just at the beginning of the zone.

Many of the participants describe that this guidance and support from the team was not that of a parent, teacher, or therapist, who removed the challenges so that they could easily overcome them. Instead, the team supported the participants, expressed belief in them, and gave them strategies, techniques and focal points to concentrate on in order for the participants to engage with and overcome the challenges on their own.

The participants themselves also became sources of inspiration and role models for one another: while it is one thing to share an experience with someone from the team, it is quite another to do so with someone who has CP and who has gone through many of the same personal experiences you have. Jeppe describes this difference as follows:

“The difference is probably that many of those who don't have CP...don't have the...disadvantage to struggle with that I have...I just think it has given me a lot to be with someone without CP. But it's also good to be with someone who has CP; then you just see that there is someone who goes through the same things as you do and you can talk to them about how they manage and things like that...You get a certain unity with one another. I don't know about the others, if they, like me, have this fighter-will, but I don't think I would have this without them. It's about mirroring oneself in others.”

The participants describe in different ways how the specific we-experience of being part of a social group and community of 'peers' with CP makes them feel in control when they are skiing. They describe, for instance, that the we-experience is felt in their body, that it calms them so that they can focus on skiing instead of thinking, that it makes them experience their presence, that it expands their 'green zone', and that it's a comfort zone, where they can forget their uncertainty and focus on the experience of skiing. Ultimately, the social aspect of sharing a we-experience helps them overcome challenges that they never thought they would be able to meet. They were not afraid to fail when taking on such challenges, since they were together with others that directly share in their experience.

### **4.3 I Can Control: Extending the Field of Possible Actions**

When asked to describe the experiential difference of having been part of the winter camp, the participants generally related how the experience of dealing with challenges has become a point of departure for managing all the other challenges they face on a daily basis.

The participants described how the winter camp was a situation in which they concretely experienced how to overcome challenges. On the hill, you couldn't just take off the skis and give up, since that would only make the situation worse – it takes a lot more energy and time to walk down than ski down the hill. They were in a situation where they had to try again when they fell. In the end, the experiences they went through were not only challenging, but a majority of the participants also felt them to be painful and exhausting, a description that also resonates with how they typically described their daily experiences.

This didn't keep the participants from continuously facing their challenges, or taking on new and more difficult ones after mastering fundamental skills, such as ploughing, turning and taking the lift. It wasn't learning the actual skill itself but rather the process of engaging with something that challenges them, that they aren't able to do, and the experience and value of then finally being able to control and overcome the challenge that motivated the participants. Rikke describes this in terms of gaining trust in oneself: "You tried something new and got more confidence. [I: How?] By saying that you did it, when you finally did it and, when you didn't do it, saying: 'I must try until I do.'" Rikke further describes that she came to believe in herself during the winter camp so, when she in her daily life doubts whether she can perform a certain action, she now continuously tries until she succeeds.

Descriptions like Rikke's are characteristic of the way in which the participants recount how the winter camp has influenced their daily life after coming home. Signe describes that, during the camp, she experienced being able to do things she didn't believe were possible, and she could do them despite her constant bodily pain. For Signe, this experience has meant a lot in her daily life after the winter camp, and she gives an example of going on a fieldtrip with her school:

"I say to myself, if we are doing something with the school, you know, where I'm tired: 'okay if you could ski, being really tired and having a lot of pain in your knees...then you can also do this.' So, it's about having this constantly in mind, which I think will help me in many years to come. To have this thought in the back of my mind that, no matter how painful it is, and no matter how tired I am, I can still ski. This means I can also do this, it's nothing in comparison."

Rasmus gives another example of how the winter camp has helped him in dealing with stressed and anxious situations in his daily life.

"When I was doing exams in elementary school, I just sat there sweating all the time...and it just got worse, worse, worse and that's the way it was...I've had a really good experience with this trip and just took it as it came. We go up, and then we ski down, and we see if we fall or not...So, it's something about your having to trust yourself. Just take it nice and slow, because then you can go much further than you actually think"

This camp has additionally given Rasmus the experience and belief that he is in fact able to learn the things he wants to learn, despite his disorder. This is also the case for Frederik, who, before the camp, described that he has a 3-wheel bike, which he loves to ride. Two weeks after the camp, Frederik's parents sent a video to the team in which Frederik was riding a 2-wheel bike. The parents described this as one of Frederik's greatest wishes in life. Frederik is a person of few words and with a severe speech impediment, but Ditte gave a clear description of her experience of Frederik when she was shown the video of him riding the 2-wheel bike:

"It was so fun to watch and so lovely to see, because...I don't know if he learned to believe in himself, but there was just something that had changed and it was so great...This was something that really sunk in and showed me that our disability shouldn't stop us from pursuing the things we want...One can easily say 'I think, I'll just pass,' because we have, after all, this apology, we have our disability. We can always, especially with strangers, use it as an excuse if there is something we don't dare to do...and that's probably because people don't fully understand what it entails. Then almost always, if there's something you really feel uncertain about, you can use it as an excuse and say 'I have this disability that makes it difficult, so I probably can't do what you are asking me to do' and I just think that it may well be, that you can't do it quite like the others from perhaps school, but...it could well be that you could in fact do it. To learn how to do it is the way I think about it now"

## **5. Discussion: Self-Control in CP**

We will frame the discussion of the results in relation to the issue of self-control so as to further develop the therapeutic aspects of EC and to discuss its possible relation to CBT.

### **5.1 A Holistic View of Control: Pre-Reflective and Reflective Aspects**

The question of the pilot study was: will a model of intervention working with embodied aspects produce behavioral effects? When we interviewed the participants 2 months after the camp, they described examples of how the experience of being able to control and overcome challenges in the winter camp had given them a boost in self-confidence and the motivation to take on daily, painful, stressful and anxiety-provoking challenges. Overall, the participants tried to participate more actively in school, they were able to acquire control over stressful and anxiety-provoking situations, and some of them learned new skills, such as riding a bike, which they didn't think were possible before the camp.

Since we only interviewed the participants 2 months after the winter camp, and we didn't operate with a control group, our aim isn't to discuss whether these behavioral effects are going to be long-term. Rather, our

aim is to understand what initiated these immediate behavioral changes in order to understand the conditions under which such changes can happen and, thereby, be able to further strengthen them.

In order to validate the descriptions and evaluate them in relation to the behavioral effects, we will in this discussion create internal phenomenological consistency by dividing the specific descriptions into different themes of self-control. These themes will be corroborated by work done in EC and CBT on the issue of self-control in order to establish the external phenomenological consistency of the descriptions. This strategy of ensuring internal and external phenomenological consistency is employed so as to understand the behavioral effects of the winter camp based on the participants' descriptions.

One crucial notion for EC based therapy is 'self-experience,' which is vital in understanding self-control. Röhrich et al. (2014) stress that a holistic view of self-experience should be an overall defining feature of EC based therapy where cognitive, emotional, perceptual and physical aspects should be understood as inseparable elements of such experience and situated within a psychosocial context. The aim of holistically working with these aspects of self-experience is to influence the individual's "creativity and personal resources/skills/capabilities for effective affect- and self-regulation" (Röhrich et al. 2014, 12).

In many of the participants' descriptions after the winter camp, we see examples that relate their experiences of control in their daily life to the term, 'self-regulation'. They are able to self-regulate their experiences of uncertainty, stress, pain, anxiety and doubt in their daily life in order to, for example, partake in social events. They are also able to self-regulate their learning processes and keep engaging with challenging activities until they succeed in doing them.

The term 'self-regulation' is an integral part of CBT's conceptual and therapeutic framework, but it's typically understood at the reflective level. It concerns self-regulating learning processes, which require controlling and monitoring one's own actions in order to meet goals of self-improvement (Paris & Paris 2001, 89), as well as emotional self-regulation, namely the monitoring, evaluating, and modifying of one's emotional reactions in order to achieve such goals (Thompson 1994, 27-28). This means that self-regulation here refers to higher cognitive abilities and executive functions of control, monitoring and evaluation.

Other terms within CBT that are relevant for understanding self-control in the participants' descriptions, terms such as 'self-efficacy', 'self-confidence', 'motivation' and 'resilience', also operate on such a reflective level. For instance, Bandura's definition of 'self-efficacy' broadly refers to the agent's personal belief in her ability to exercise some measure of control over her own functioning and environmental events (Bandura 1997). For Bandura, there would be no motivational factors for acting if agents didn't understand and believe in their own abilities to exercise control in the case of surprise or difficulty (Bandura 2006, 170).

However, if we look at the winter camp, the shift in the participants' experience of control in, and cognitive response to, uncertain and challenging activities is related to a shift in their bodily experience. The participants described a difference between an experience of having to attend to and acquire control over

their bodies and an experience of being in control, where they were relaxed and focused on their surroundings, letting their movements and actions depend on what happened around them. This shift in the experience of control gives the participants the motivation and courage to, despite their motor control disorder, make decisions and act in ways that might be uncertain.

In order to understand these descriptions, we need to operate with an expanded definition of control that doesn't rely solely on reflective abilities. This is found in EC, where control is experientially understood and where one can distinguish between two different ways of experiencing control: 1) one *feels in control* and 2) one has the *sense of exerting control* (Pacherie 2007, 18). The former refers to the experience of control wherein one feels that an action happens exactly as expected and that one is fully in control. This feeling of control can be described as pre-reflective, non-observational, and non-conceptual, and relates to motor and situational control. The sense of exerting control is experienced as demanding, since the agent has to exert control in order to maintain an appropriate action plan or thought. Experience can here be described as reflective, or observational, and relates to rational executive control.

Thus, it's crucial to point out that, in addition to the reflective level, there is a pre-reflective level of self-experience that is fundamental to EC's understanding of control (Gallagher 2000, 2012, 2013). It should in fact be a defining feature of an EC based therapy to include and to work with this pre-reflective level of experience, since it plays a crucial role for understanding the embodied relation between cognition and behavior in an EC theoretical framework.

It is necessary to include the pre-reflective level of experience in order to understand the participants' behavioral effects. The participants described how, after the camp, they performed actions or learned skills that they wanted but didn't think they were able to do. This means that, even though these actions were physically possible, and the participants desired to do them, they nevertheless didn't do so before the camp. At the camp, they experienced going through bodily activities in which they were able to control and overcome challenging situations. It's the bodily self-experience of 'I can' control my movements during challenging activities despite my motor control disorder that grounded the cognitive development that the participants went through in the winter camp. This gave them an experiential foundation for increased self-control at the reflective level, which means increased self-efficacy, self-regulation, motivation and resilience. Thus, bodily activities and experience should be defining features of EC based therapy, since they are necessary components for working with the pre-reflective as well as the reflective level of self-control.

This has also been emphasized by other EC based model of interventions such as that developed by de Haan et al. who argue that one crucial feature of EC informed methods of treating OCD is "taking patients' experiences seriously and properly investigating these experiences, rather than dismissing them as 'maladaptive' effects of patients' faulty philosophical orientation" (de Haan et al. 2014, 48). Röhrich et al. 2014 combine EC with so-called Body Psychotherapy (BPT) (see Röhrich 2014 for an overview of BPT)

and argue that body activity and experience are fundamental for diagnostic and therapeutic processes. Due to their bodily focus, Röhrich et al. nevertheless construe EC based therapy as standing in opposition to the focus and strategy of so-called ‘talking therapies,’ which CBT is taken to be a part of.

However, adopting a holistic view on self-experience in EC means stressing the pre-reflective as well as the reflective level of experience. By including bodily experience and activities, the aim shouldn't be to exclude the reflective level of therapy, as it is a fundamental principle in EC that the two levels of experience are related to each in the experience of control (Gallagher 2012, 2013). In this respect, there is an obvious possibility for EC and CBT to work together, since the latter has done extensive therapeutic work on self-control at the reflective level. This is seen in the design of the winter camp, where the team gave the participants reflective coping strategies they could use to deal with challenging situations. There is an equal possibility for CBT to include a new aspect of pre-reflective self-experience in its therapeutic focuses.

## 5.2. Situating Self-Control and Exposure

As mentioned above, by understanding bodily experiences in the feeling of control as situated, one can gain better insight into, for instance, what it meant for the participants to grow more relaxed and focus on their surroundings, letting their movements and actions depend on what happened around them. Thus, one way to work with the pre-reflective level of control is to situate bodily experiences.

De Haan et al. (forthcoming) have argued for the same aim of situating self-control in relation to OCD. They argue that there is a tendency for patients with OCD to exert rational control over their actions so as to reflectively try to perform such actions in the best way possible. Relying solely on rational control for performing actions induces self-distance from the pre-reflective experience of acting. The patients become mentally ‘trapped in themselves,’ so to speak, which counterproductively leads to a greater experience of uncertainty, coping and worrying. Thus, EC based therapy should help the patients to stop trying to reflectively and rationally control their actions and, instead, encourage them to make the shift towards situated and pre-reflective control.

How do such suggestions relate to the third wave of CBT? Metacognitive Therapy (MCT) (Wells 1995, 2000, 2005) is an approach in the third wave that might preliminarily seem to be in contrast to EC, insofar as it focuses on meta- and rational control. The fundamental point in MCT, however, is to emphasize that the real problem to be dealt with lies in the difficulty of controlling aspects of metacognition, such as extensive and unreasonable coping strategies, worrying and monitoring. Whereas traditional “CBT is concerned with testing the validity of thoughts...MCT is primarily concerned with modifying the way in which thoughts are experienced and regulated” (Wells 2008, p. 652). This concern is closely related to EC based therapy where there is a paradigmatic shift in emphasis from the “what” of experience to the “how” of experiencing (Röhrich et al. 2014, 12).

One way to regulate thoughts in MCT is exposure, where the aim is “to test the accuracy of worry content against perceptions of real situations. This was intended to strengthen the replacement meta-belief that worries are inaccurate and therefore offer little advantage for coping” (Wells 1995, 314). Contextualizing meta-cognition by such a process as exposure is a way to foster a more open, aware, and active approach to living: “when a person is open, aware, and active, a steady foundation is created for more flexible thinking, feeling, and behaving. Metaphorically, it is as if there is greater life space in which the person can experiment and grow and can be moved by experiences” (Hayes et al. 2011, 160).

In the case of anxiety disorder, Meynen has argued that the exposure component of MCT, and CBT in general, is in fact understandable from an EC perspective (Meynen 2011b). It’s the situated experience and actual bodily activity of the individual that should be used as a means to correct metacognitions. This was also one of the main points of the winter camp, since it’s the actual situated experience of engaging with uncertain and challenging activities that helped the participants let go of rational control, worrying, and metacognitive coping, and made them experience a feeling of being in control.

Exposure is a well-documented and discussed therapy in CBT (Lindsay et al. 1997; Chambless & Ollendick 2001), but it’s typically described using behavioral terminology. Here the idea is “to expose patients to fear-provoking stimuli in a repeated and systematic manner in order for them to acquire a sense of safety in the presence of the formerly feared stimuli” (Bentz et al. 2010, 223). In EC, the use of notions such as ‘stimuli’ is problematic, since the experience of the world isn’t understood as a static stimulus. Perception and action are intrinsically linked in EC, and we enact our experiences of the world (Noë 2004). Thus, the use of notions such as ‘affordances’ or ‘cues’ would be more appropriate in EC, since they emphasize that the world shows itself as affording and presenting cues for actions.

Klinke and Jónsdóttir (2014) suggest working with environmental affordances as an EC based approach to clinical practice for chronic obstructive pulmonary disease and, in the case of depression, Meynen stresses the importance of continuous contextual cues, so that one’s decision-making is in ‘online’, experienced engagement with current situations (Meynen 2011a). While these two examples might be terminologically and theoretically in line with EC, they don’t present any practical proposal as to how to perform such affordance or cuing therapy. In that respect, exposure therapy coming from CBT is relevant, since it’s already a well-established therapy of how to situate bodily experiences.

Thus, in relation to situating bodily experience and control, we see possibilities for EC and CBT to work together. The former presents a new theoretical framework and the latter a well-established therapy of exposure that can be used for further development in both frameworks. In addition to exposure therapy, other therapies, such as Mindfulness-Based Cognitive Therapy (MBCT), can also be seen as fruitful for EC in contextualizing bodily-experience. In MBCT, the aim is to increase one’s sensitivity to the environment in order to enhance self-management and successful coping (Hayes et al. 2011, 146). EC is highly influenced



by meditation and Buddhism (Varela et al. 1991), so it possible relation to MBCT is somewhat obvious. It's necessary to emphasize, nevertheless, that EC based therapy should always include bodily, situated and enacted activities and that it wouldn't be sufficient to rely solely on talk sessions such as 'change talk' or motivation interviews (Hayes et al. 2011, 149).

### 5.3 Enacting Self-Control in Committing Therapeutic Engagement

To embody and situate experiences of control in EC means to do so in a social context. In the winter camp, part of this context was the relationship between the professional team and the participants, which the participants described as fundamental for their development. The team guided the participants, expressed belief in them, and gave them strategies, techniques and focal points to concentrate on so that the participants could control and overcome the challenges themselves.

It's a crucial point in EC that cognition is something you enact and actively develop. A defining feature for EC based therapy is therefore that the therapist support such enacted development. Whether the embodied and situated activities are done in physio-, occupational or psychotherapy, they should be something that one actively goes through oneself with sufficient guidance and collaboration. This additionally means that another defining feature in EC based therapy is that the therapist shouldn't take up an observational and distancing stance, but should *engage* with the person and become an enacting part of her therapy, bodily activities and experiences (Röhrich et al. 2014). This should be done in order to perform the therapeutic guidance and collaboration in the best possible way. In the winter camp, this meant that both the ski-instructors and the staff from HEC skied down the hill with the participants. For some of the staff, especially the persons with CP, this was as challenging for them as it was for the participants.

In the EC literature, the notion of 'engagement' is crucial and can be used to understand the relationship in therapy. Satne and Roepstorff have recently defined engagement as involving two aspects: 1) an experiential aspect and 2) a normative aspect (Satne & Roepstorff 2015, 19-20). The first aspect illustrates that engagement with others is an affective, emotional and reciprocal we-experience and that communication with others should also be understood in such terms. For communication in a therapeutic setting, EC based therapy focuses on embodied and situated engagement in order to incorporate non-verbal expressive behaviors such as movement, posture, gestures, bodily and facial expressions, etc. into their communicative praxis. Øberg et al. (2015) and Gallagher & Payne (2015) have shown how EC can illustrate new ways of scaffolding communication between therapist and patient and, thereby, contribute to the development of the therapist's clinical reasoning and guidance.

Satne and Roepstorff describe the normative aspect of engagement by emphasizing that engagement is a *commitment* between persons (Satne & Ropstorff 2015, 20). The notion of 'trust' is important in describing this interpersonal commitment in our case, since it has been argued that the cognitive and strategic

component of trust is a way to manage uncertainty (Becker 1996, 45). For the participants in the winter camp, this uncertainty arose because they didn't have sufficient knowledge to understand and rationally control the challenging activities. They lacked knowledge of the situation, and were therefore vulnerable but, as Baier highlights, trust is precisely the acceptance of this vulnerability (Baier 1986, 235). For the participants, this meant accepting their experience of uncertainty while going through the challenges, and accepting and committing to the purpose of the camp, namely the overall idea of going through such challenges. In addition, this meant that the participants put their trust in being guided by and collaborating with the team so as to overcome the challenges.

From a therapeutic perspective, trust is an attitude in which the therapist recognizes and attends to the 'patient' or 'client' as a person. When understood as recognition, trust means upholding the autonomy and self-control of the person (Bernstein 2012). To trust is therefore for the therapist to actually abandon control over the actions performed by the person they are working with so as to enforce the latter's autonomy and self-control. In the winter camp, the team worked with such strategies of trust and recognition in order to encourage the participants to actively go through the challenging activities on their own. The team guided the participants and gave them conceptual tools and coping strategies, but with the overall aim of enhancing the participants' experience of self-control.

Such a description of the therapeutic relation in EC based therapy has similarities with attempts in the third wave of CBT, especially with Acceptance and Commitment Therapy (ACT) (Hayes 2004). As a way to acquire contextual control, ACT works with psychological attitudes of acceptance and commitment, which we have discussed above in relation to trust. Acceptance is understood as the "active nonjudgmental embracing of experience in the here and now" (Hayes 2004, 656), which, in our case, would relate to the participants' experience of uncertainty. Commitment refers to committed actions such as exposure, for instance. The aim in these actions is to increase psychological and behavioral flexibility, which is "the ability to contact consciously the present moment and the thoughts and feelings it contains more fully and without needless defense, and based on what the situation affords, to persist or change in behavior in the service of chosen values" (Hayes 2011, 155).

Therapeutic processes are experiential and contextual in ACT, but it's crucial for ACT therapists that 'you do as you say', which means that therapists should also work with these processes of acceptance and commitment both on their own and in their relation to their clients. It's a symmetric relationship where therapists should "put themselves into the shoes their client..." (Hayes 2004, 652). In ACT, there is no fundamental distinction between therapist and client with respect to the processes that need to be learned (Pierson & Hayes 2007, 225).

EC based therapy and the third wave of CBT seem to agree on the assumption that the therapeutic relationship is about sharing the same experiences, processes and engagement. As we saw in the winter

camp, this relationship was crucial in developing the participants' experience of control. Hayes et al. nevertheless point out that, whereas this assumption has some merit, it hasn't been empirically tested (Hayes et al. 2011, 159). EC could provide a theoretical and methodological basis for testing such an engaging relationship, whereas the practice of, for example, ACT could illustrate ways of training EC based therapists.

## 5.4 Self-Control in a Group Context

In the winter camp, the participants described how the social context of performing actions on the hill, while the other participants were watching and cheering, heightened their motivation to the challenging activities they were presented with. Participants described this social context as playing a fundamental role in the development of their experience of control and, in EC inspired social neuroscience, experimental research has shown that the social context and gaze of others is an influential reward component that changes the neural mechanism of action control (Pessoa & Engelmann 2010; Schilbach et al. 2010, 2012; Gangopadhyay & Schilbach 2012). Socializing the therapy process should therefore be a defining feature of EC based therapy.

However, the social influence on the participants' experience of control went beyond the others' watching and cheering. The experience of being part of a group was emphasized as a highly influential factor in the participants' experience of control when they were skiing. Röhrich et al. have emphasized the use of 'group therapy' in EC based therapy and presented the T-group or encounter group model as an example (Röhrich et al. 2014, 15-16). The idea of 'group therapy' is not an EC contribution to therapy, and it has been included in many different ways in CBT. Nevertheless, as Röhrich et al. stress, there is some hesitancy in using group therapy in CBT, since it's difficult for the therapists to structure and control the therapy session. It is possible that, within a group context, the exposure to strong emotions that become too intense might lead to further traumatic experiences (Röhrich et al. 2014, 16).

This is definitely true, but a crucial point from the winter camp is that the sharing of experiences with other 'peers' strongly motivated the participants to take on challenging activities and, thereby, acquire a feeling of control. The use of peer and mutual support groups in cases of mental disorder is in fact well-established and discussed. Davidson et al. (1999) highlight four beneficial aspects of using such support groups in therapy that are relevant for our case: 1) Sharing similar life experiences with others can increase a person's understanding and acceptance of her situation and autonomy. 2) A structured process of social interaction allows for adopting socially valued roles in which people are not restricted to the passive role of "patient", but wherein they serve a reciprocal role of providing feedback and assistance to others as well as receiving feedback from them. 3) Mutual support exposes individuals to successful role models, offers them new tools, such as coping strategies and alternative perspectives, provides an opportunity for vicarious learning and modeling and, finally, enhances problem-solving skills. 4) Mutual support offers a *cognitive*

*antidote* to participants' problems by offering new worldviews and new ways of viewing themselves. It also offers an *environmental antidote* to the realities of social isolation (Davidson et al. 1999, 168).

Structuring group experience in therapy so as to combine these four aspects is a beneficial way to offer support. The camp design can be seen as an attempt to offer such supportive we-experience within the entire group. The professional team designed the group structure in detail to create a committed community where all the participants were included in the group from the very beginning, and no one was left out. This meant making the participants feel they had a legitimate voice and value, and encouraging them to actively participate in the group activities. The aim was to remove or at least minimize any hierarchy in the group, so that each and every participant would experience the possibility of being himself or herself and would be motivated to contribute to the group. This was done by stressing that everyone contributes differently to the group, but that all contributions are equal in value. Whether the participants were good at skiing, supporting the others, or had a third role, the team established that each of these contributions was valuable to the group as a whole.

This strong, committed group-experience became crucial for the participants' development, since there were as many action failures as there were successes. However, the participants all shared in one another's risks, failures, and successes together, which changed their attitude to taking risks, failing and facing challenging and uncertain activities. For the participants, it was about sharing a process of having to control challenging and uncertain activities while having CP. The experience of this learning process was a we-experience in which we all risk, we all fail, but we all succeed and we all can control.

The social we-aspect in EC based therapy shouldn't be restricted to group therapy alone. Rather, as de Haan et al. (2014) stipulate in their discussion of OCD, this social component should be seen in a more encompassing and global view, one that understands that any treatment of the individual must keep in mind the daily environment, partners, friends and family with which and with whom she is always in interaction. We didn't try to achieve such an encompassing view in the winter camp, but we did present one way of structuring a form of 'group therapy' by using the group activity of sports in the structuring process. Using sports as a model of intervention has already been shown to aid executive function development in children (Diamond & Lee 2011) and has been used as a way to combine EC with the tradition of Adapted Physical Activity (APA) (Duesund & Skårderud 2003, Duesund 2008). Thus, sports camps may be a future collaborative possibility for both EC and CBT to work on.

## 6. Conclusion

In this paper, we have presented an EC based model of intervention for working with self-control in CP in order to further develop a framework for EC based therapy. We have discussed such a framework in relation to the third wave of CBT and clarified the following key aspects of an EC based therapy:

1. Adopt a holistic view of self-experience, which means working with both pre-reflective and reflective levels of experience and understanding cognitive, emotional, perceptual and physical aspects of such experience as inseparable elements within the individual's psychosocial context.
2. Include and work with the pre-reflective level of self-control, which means working with the distinction and shift between two experiences of control, namely between the feelings of being in control and of exerting control.
3. Focus on bodily activity and experiences, since they are necessary components for working with the pre-reflective level of control.
4. Support enacted development, which means engaging with the person and becoming an enacting part of their bodily activities and experiences.
5. Socialize the therapy process, which means including group therapy and more encompassing social contexts.

In relation to these key aspects of EC based therapy, we see interesting possibilities for EC and the third wave of CBT to work together in the future.

**Informed consent:** Informed consent was obtained from all individual participants included in the study.

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## Chapter 9

### How Far Can We Extend the Lab?

### Open Experiments in Social Cognition

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# How Far Can We Extend the Lab?

## Open Experiments in Social Cognition

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### 1. Introduction

Over three decades ago, Neisser criticized the discussions on social cognition for being mainly observational and detached from the social world. He made an interesting, yet surprising, suggestion, namely that scientists could benefit from looking at professions in the theater for inspiration, since the expertise of such professions consists in manipulating social impressions. According to Neisser, the reason why this isn't done is that academics don't take notice of professional accomplishments outside the university, since such professions lack the necessary scientific controls for illuminating issues on social cognition. For Neisser, this opinion means that academics are typically more interested in theoretical issues and concepts in social cognition than in the actual social phenomena (Neisser 1980).

Neisser's proposal is especially interesting today, since the discussion of whether the study of social cognition should be rooted in observation or engagement is flourishing in current debates (e.g. de Bruin et al. 2012; Schilbach et al. 2013; Overgaard & Michael 2013; Satne & Roepstroff 2015). That these scholars should be more interested in theoretical issues and concepts in social cognition than in the actual social phenomena is too strong a critique. The issue is more a matter of *how* to actually develop a method, such that using theatre would be beneficial for illuminating issues in social cognition.

We will not partake in the discussions of whether the study of social cognition should be rooted in observation or engagement but, as a point of departure, adopt a second-person and engaged study of social cognition. We do so as a way of further developing a method that combines social cognition and theatre. The overall question we investigate is: Can theatre be used for a second-person investigation of social cognition? In order to narrow down such a large question to one specific case, we focus on a topic already extensively discussed in social psychology, namely the social understanding of persons with physical disabilities. We present and discuss a specific social cognitive and theatre experiment: a one-time theatre performance called *Humane Liquidation* (Human Afvikling in Danish). Although this paper presents some preliminary results from this experiment in relation to the social understanding of persons with physical disabilities, the main question we discuss is methodological: "*Can theatre be used for a second-person investigation of the social understanding of persons with physical disabilities?*"

We argue that the audience's embodied and engaged experience in the theatre performance can be seen as the experiment's independent variables, and we do so by investigating three different levels of dependent variables, namely 1) the audience's implicit associations, which are measured by the IAT test, 2) the

audience's self-reports (judgments and evaluations), which are measured by quantitative questionnaires and 3) the audience's experiences of the theatre performance, which are investigated by the use of phenomenological interviews. We end by pointing to future directions of developing this combination of social cognition and theatre performance, and highlight the use of the so-called Engaging Questionnaire we developed during the project and the use of phenomenological interviews.

## 2. Opening up Cognitive Science

As stated by Goldman and de Vignemont, the spectre of embodied cognition (EC) is haunting the laboratories of cognitive science (Goldman & de Vignemont 2009). In the laboratories of social cognition, this is especially the case because of the recent interactive turn (de Jaegher et al. 2010). This turn is comprised of a group of different views whereby EC joins forces with enacted, embedded and extended cognition in order to present a different way of studying social cognition than seen in the so-called mindreading approach. According to the interactive turn, this approach focuses solely on explanations of social cognition that read cognition in mental terms and situate it within the skull, and it adopts an observational and spectator stance for doing so. This stance is characterized by 'isolation paradigms' and 'experimental quarantines' of passive observation (Becchio et al. 2010; Schilbach et al. 2013).

For EC and the other E-approaches, cognition isn't skull-bound, but is rather something experiential and emotional that we bodily enact in the world, together with others and through the use of technology (Varela et al. 1991; Clark 1997, 2008; Wilson 2002; Noë 2004; Gallagher 2005; Thompson 2007, 2014; Gallagher & Zahavi 2008; Chemero 2009; Rowlands 2010). The interactive turn therefore aims to develop a so-called second-person study of social cognition (Thompson 2001), which should include aspects of experiential and emotional engagement and reciprocal interaction when trying to understand and study social cognition (de Bruin et al 2012; Schilbach et al. 2013; Satne & Roepstorff 2015).

As has become explicit in current discussions in social neuroscience, to include second-person aspects of engagement and interaction is problematic, since a brain scanner's technical conditions limit the possibilities for interpersonal engagement and interaction. Schilbach et al. (2013) have presented and discussed different creative second-person solutions, such as 'hyperscanning' (Montague et al. 2002), avatar-based interactive video platforms (Bente et al. 2007) and live video screening of the interactive partners' faces in the scanner (Saito et al. 2010). However, setting up experiments for social cognition, or for any topic, depends on the questions, theories and mindsets that frame the setting, and is only as strong as its framing (Webster & Sell 2014, 10). Gallagher et al. (2013) have criticized Schilbach et al.'s solutions and overall attempt for falling into the trap of neurocentrism, which conceives of the brain in representational and computational term. This trap directs Schilbach et al. towards questions, methods, technologies (e.g. fMRI) and, ultimately, answers in

studying social cognition that are more in line with traditional cognitive science than with the second-person study of social cognition. Schilbach et al. in fact endorse Gallagher et al.'s proposal that, if we want to account for a picture of social cognition that happens in the world rather than in the brain, scanner, or lab, we need to employ a multiplicity of methods, of which neuroscience is one among many (Gallagher et al. 2013, 422).

## 2.1. A Pragmatic Change of Mind

Emphasizing methodological multiplicity and interdisciplinary collaboration is also seen in the Open MIND project, an attempt to cross-fertilize cognitive science and the Open Science movement. As a point of departure, this project is an exercise in editorial open-mindedness and an experiment in open access publishing but, in their editorial paper, Metzinger and Windt describe why a new open-minded epistemic practice is necessary in cognitive science. Although great progress has been made during the last five decades in cognitive science, it is not at all clear what combination of methods, what type of theoretical approach, what kinds of questions and exactly what combination of conceptual and empirical tools will facilitate epistemic progress (Metzinger & Windt 2015, 3). For Metzinger and Windt, part of the solution is partly pragmatic, and an integral part of this is to develop new forms of interdisciplinary collaboration in cognitive science.

In, *The Embodied Mind*, one of the most pivotal texts in EC, Varela et al. acknowledge such methodological multiplicity and interdisciplinary collaboration, but part of their original contribution has, nevertheless, been ignored in cognitive science. For Varela et al., pragmatics are an integral part of embodied cognitive science, where the notion of 'pragmatism' can be define as the implementation of techniques, means and know-how, and refers to how well something adapts to its situation (Depraz et al. 2003, 17). However, whereas Metzinger and Windt find the pragmatic solution within science, Varela et al. find part of this pragmatic insight in many of the professions working with experience in human practice and interaction, such as education, sports training, therapy, and especially the Buddhist practice of mindfulness meditation. The latter have become the foundation for what some call a new era for mind studies, namely Contemplative Science (Deborges and Negi 2013).

Varela et al.'s pragmatic focus is, as clearly stated by Varela himself, to propose a radical transformation of the mindset of doing cognitive science:

"To the long-standing tradition of objectivist science this sounds anathema, and it is. But this is not a betrayal of science: it is a necessary extension and complement...It requires us to leave behind a certain image of how science is done, and to question a style of training in science which is part of the very fabric of our cultural identity" (Varela 1996, 347).

Thus, the real reason why EC is haunting the laboratories of (social) cognitive science isn't theoretical, or for that matter technological, but pragmatic: it questions the very core of how cognitive science is done.

Problems with the current mindset of cognitive science have also been emphasized by other scholars in EC such as Gallagher and Marcel. They argue, by pointing to Donaldson (1978), that the academic and analytic attitude that is the goal of western schooling detaches the scientist from his determination by worldly and pragmatic context. Qua scientist, we are of course embedded in a social scientific setting, and we embody and enact the rules of conduct for this setting, but the questions, methods, and answers of cognitive science are to a great extent disembodied and decontextualized (Gallagher & Marcel 1999, 287). So, if we for example want to understand socially contextualized cognition, it is problematic to do so by setting up questions and experiments that from the very beginning focus on abstract cognitive and behavioral components (ibid).

This means that we shouldn't only progress theoretically or only have an interdisciplinary focus when developing a second-person study of social cognition, but should in fact cultivate a new pragmatic mindset for doing cognitive science. In this respect, Neisser's proposal of exploring theatre becomes interesting, since it's a way of opening up the study of social cognition so as to investigate what happens in the world rather than solely in the lab.

## 2.2. Theatre as Social Engagement

Theater can be understood in many different ways but, from the perspective of theater and performance studies of so-called *theatre performance*<sup>54</sup>, the contemporary way of thinking about theater has in fact taken a cognitive turn (McConachie & Hart 2006). There is extensive literature on this turn (e.g. Zarrilli 2004; Cook 2007, McConachie & Hart 2006; McConachie 2007, 2008; Blair 2008; Di Benedetto 2011; Nicholson 2011; Shaughnessy 2012), but the different scholars mainly use three notions to understand the performance in cognitive terms, namely: 1) Embodiment, 2) Engagement and 3) Transformation.

Embodiment is used as a way of understanding the 'affective' effects that the performance has on the audience (Thompson 2009; Nicholson 2011), where the audience experiences 'being kinaesthetically moved' (Fenemore 2003, 112). Shepherd states that it is a way of recognizing that meaning in performance doesn't dependent on the semiotics of the *mise-en-scène*, but involves the embodied understanding and experience of the audience (Shepherd 2006). This understanding is, according to Shaughnessy, due to the "spectator's felt response to the experience of liveness, being in a shared space and being affected by the haptic, visceral

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<sup>54</sup> It's also called *applied theatre* or *applied performance*, but we will use the term of 'theatre performance' for the sake of simplicity.

qualities of work which can ‘touch’ them (sometimes literally). Our embodied responses involve us in empathic engagement” (Shaughnessy 2012, 48).

The notion of ‘engagement’ is used to emphasize that, in theatre performance, the distinctions between creator/performer/perceiver are blurred, as performers and audience are in a shared and creative dialogue (Shaughnessy 2012, 11). Other notions used to describe such dialogue are ‘collaboration’, ‘interaction’, ‘immersion’ and ‘participation,’ all of which are supposed to highlight the fact that, through the embodied nature of both performer and audience, they are reciprocally sharing a space and an experience (Shepherd 2006: 336–7).

The idea and notion of ‘transformation’ is already seen in, for example, the works of theatre directors such as Brect (1964) and Boal (1985), where theatre is used as a tool to help people explore their own communities and possibly change them. In theatre performance, this change is described by understanding theatre as an encounter with the social community (Taylor 2003) or as a public and social event (Schechner & Thompson, 2004). The participatory performance is then used to ‘effect’ social change through its embodied ‘affect’ (Nicholson 2005; Thompson 2009), whereby the audience members are seen as ‘active producers,’ rather than consumers. Social transformation can happen in different educational, social and communal contexts, but the overall strategy is “to find new ways of engaging audiences as participants, developing, where appropriate, interventionist strategies to challenge or to transform existing systems of representation, hierarchies and ideologies” (Shaughnessy 2012, xvi).

From the perspective of theatre performance, cognitive science is fruitful, since it can be used for understanding and designing the embodied, engaged and transformative aspects of the performance. The question is whether, as proposed by Neisser, the performance can also be fruitful for a second-person study of social cognition?

### **3. Method: Theatre and Experimental Design**

To try to answer this question, we set up a social cognitive and theatre experiment, a one-time theatre performance called Humane Liquidation (Human Afvikling in Danish), which premiered at the Royal Danish Theater September 22, 2014. The performance lasted for 1.5 hours, and there were approximately 1100 people in the audience.

#### **3.1 Theatre Design**

The theatre performance was designed as an autobiographical performance about Jacob Nossell, a 26-year-old man, who lives with hemiplegic cerebral palsy in his left side, and who has a speech impediment.

Autobiographical performance is a way of articulating, exploring and interrogating a person, identity and subject through embodied and engaged strategies. Such strategies can be seen as the experiment's independent variables, and were based on the expertise and profession of the director (Thomas Corneliussen) and on his team's ability to create a meaningful theatrical and aesthetic narrative and performance. Part of the strategy was to use loving and/or raw humor as a way of 'disarming' or freeing the audience members of their habituated prejudices and ideas.

The narrative of the performance begins by introducing Nossell and then follows him as he goes through the steps of a normal day, first getting up in the morning, then going to class at the university, and finally hanging out with friends after class (*part 1*). After this first introductory part, the performance can be divided into three parts that deal with three crucial issues in his life: employment after university (*part 2*), finding a girlfriend (*part 3*), and parenthood (*part 4*). These four parts of the performance were created in close collaboration with Nossell and included documentary aspects of his life that were presented either from his own perspective or from that of science and society. Throughout these four parts, there were scenes in which the narrative stopped, and meta-reflected on how Nossell was portrayed in relation to the issues of daily life, employment, relationships and parenthood.

Documentation material from 'real life' was used in order to illustrate the difference in perspective, i.e., between Nossell's own perspective and that of science and society, on issues such as diagnosis, the prospect of future employment, relationships and parenthood. The material was presented in the form of audio tapes, videos, statistical tables, infographics, pictures and drawings. For example, in *part 1*, Nossell describes the experience of living with congenital brain damage and, in the same part, audio/visual documentation presents a neurologist describing Nossell's brain damage in relation to an MRI scan of his brain. Nossell's specific medical journal and diagnosis were also presented in relation to medical and diagnostic statistics of cerebral palsy in the Danish society (these statistics are from Michelsen 2006).

In the next three parts, the same structure was applied, which meant that Nossell's perspective on the matters of employment, relationships and parenthood were presented in relation to medical and societal perspectives. For example, real life audio documentation was presented from job interviews that Nossell had been to; this material was again related to the employment statistics for persons with CP in Denmark. Prior to the performance, Nossell also took a DNA test, the results of which were both considered by a professor in genetics, whose discussion was presented in an audio recording, and related to Nossell's own perspective of, and reflections on, having a child.

Nossell was joined on stage by actor Kristoffer Fabricius, who guided the audience through Nossell's life and through the different medical and societal perspectives presented. This was primarily done to help Nossell perform 1.5 hours of demanding theatre, and to help the audience understand Nossell, since he, as mentioned, has a speech impediment. The relation between Nossell and Fabricius was also used as a way of



illustrating their difference; this was accomplished by having Fabricius alternate between moving and speaking like Nossell, namely acting as if he had CP, and foregoing the motor control disorder to play Nossell in a 'normal' way. The latter was done to make the audience reflect on how they would experience Nossell if he didn't have a physical disability.

The scenography was minimally designed; the main prop was an 11m x 2.5m projection wall, which was used to display the different visual material. Other main props included 3 small stools, 1 leather stool with a connected small table, and 2 bar stools that were brought in when needed. The projector was used to show the videos, statistical tables, infographics, pictures and drawings, to subtitle Nossell and to create the background of 'real life' locations and situations, such as Nossell's apartment, a hospital, a bar or streets in Copenhagen.

The lighting, sound and music were used to give the performance a more cinematic perspective, and to support the 'real life' locations in some of the scenes. The lighting and sound was designed to create an experience of presence, namely of being together with Nossell in 'real life' situations, and to create specific kinds of moods for the specific situations.

### 3.2. Experimental Design

Autobiographical performance is a powerful medium for inspiring potential transformation (Thompson 2009; Nicholson 2005, 2011). Part of this is due to the setup of the theatre performance, since, in contrast to encountering Nossell for the first time on the street, for example, the theatre setting structures the encounter, so that the audience's reaction is both physically and psychically confined. They are restricted to their seats, and it's difficult to either walk away from or ignore Nossell, since he is right in front of them on stage. At the same time, the audience members are committed to Nossell in the encounter, since they have themselves chosen to be in the theatre, and are encountering Nossell on stage and engaging with him in a way that is more reassuring than an everyday encounter or engagement would be. They are sitting at a certain distance from Nossell and don't have to physically interact with him. So, as a point of departure, we have the audience members in a situation where we are more or less able to control their encounter and engagement with Nossell.

The audience can of course walk out of the theatre, and things might happen in the performance that we didn't expect. This means that, in contrast to a laboratory setting, theatrical performance doesn't operate with the same level of controls. As we will show, what it lacks in controls, it gains in engagement. However, in the engaging experience lies the transformative effect. This means that not only should the experimental design be able to test the audience's engaged understanding of Nossell, but it should also be able to test the transformation of this understanding during the performance.

Before describing how we aim to test this transformation, some ethical reflections on this transformation are required. As with any social experiment that includes persons, we need to acknowledge, and develop protocols for dealing with, the ethical issues in the experiment. In using theatre in social cognition, this relates primarily to the transformative element of the theatre performance. Detailed protocols for dealing with such transformative elements need to be drafted for the future development of combining social cognition and theatre. That being said, we informed the people participating in the project about the necessary details for participation ahead of time and included those who still wanted to participate. They gave their consent, were free to leave the project at any time, and were throughout the project encouraged to contact us if they had any questions. The project finished, for some of the participants, with a personal interview, where the participants were informed about the meaning of the IAT-test they had taken and had the opportunity to talk about any unpleasant experiences they might have had during the project.

We used a focus group of 15 Danes—8 women and 7 men between the ages of 22 and 59—who were seated sporadically in the theatre, but with a good view of the stage. The group was chosen two weeks before the performance by randomly selecting people between the ages of 18 and 60 who were walking past the Royal Danish Theatre. Participants recruited were the ones that, after being informed that they were participating in a research project, still wanted to participate. They were not informed of the kind of research project, but only told that they were going to see a theatre performance.

We used three different methods to investigate the focus group's understanding of Nossell, the first two of which are typically used in measuring the social understanding of physical disability: 1) the IAT test, 2) quantitative questionnaires, and 3) phenomenological interviews. This means that the dependent variables of the experiment were respectively the focus group's implicit associations with, self-reports on (judgments and evaluations of) and experiences of physical disability.

### **IAT (Implicit Association Test)**

IAT is a standardized test typically used in social psychology for studying interpersonal attitudes (Greenwald et al. 1998). It works as a latency-based method that indirectly measures strengths of associations between, in our case, persons with and without disability and attributes of either pleasant (good) or unpleasant (bad) valence. The participants do so by classifying a word or picture according to an appropriate concept discrimination (person with or without disability) or attribute discrimination (pleasant or unpleasant valence). The IAT measurement is based on the latencies of responses to these categorization tasks, where the difference in response times is interpreted in terms of association strengths.

The IAT test can be taken online and explicitly in relation to physical disability. The focus group was instructed to do so a week before the theatre performance and first thing the day after the performance. The results are divided into 1) a slight, 2) moderate or 3) strong automatic preference for abled people compared

to disabled people; 4) a little to no automatic preference between abled and disabled people: 5) a slight, 6) moderate or 7) strong automatic preference for disabled people compared to abled people, and 8) too many errors to determine a result.

### Engaging Questionnaires (EQ)

Quantitative questionnaires have already been used to measure the self-reports of Danes (Olsen 2000) and Englishmen (Staniland 2009) in large-scale studies of these populations' perceptions of disabled people. Inspired by the questions used in these studies, we created 16 questions (see figure 4b) that were in accordance with the theatre performance and that were specifically related to cerebral palsy and Nossell. The questions were divided into 4 sections relating to the 4 parts of the theatre performance. The performance stopped and the questions were posed on the projection wall on the stage (see figure 1) and announced by a speaker. The answers were submitted by using an interactive and mobile device (see figure 2) that was placed in the seat of, and correlated specifically to, each of the 15 participants of the focus group.

Instead of using the exact same questions from the earlier studies, which were formulated in relation to an abstract person with an abstract physical disability (e.g. cerebral palsy), and in relation to an abstract situation (e.g. imagine that the person is sitting next to you on the bus), some questions were set up differently, so as to reflect the actual engaged experience that the audience and Nossell were sharing together. Thus, we designed the questions based on scenes and situations that the audience had just experienced and shared with Nossell, and in a way such that the participants had to either 1) answer the question relative to Nossell, e.g. 'Where would you place your quality of life relative to Jacob's?' or 2) try to answer from Nossell's perspective, e.g. 'Where do you believe that Jacob would place his quality of life relative to yours?' We call such questionnaires for Engaging Questionnaires (EQ).

The answers were given on a gradual scale from 1-10, which was primarily due to the technical design of the answering system. There was no neutral answer (e.g. I don't know), since we wanted the participants to take a stance in relation to the specific question. They were given 15 seconds to answer each question.

However, another 235 people out of the 1100 people in the audience functioned as an anonymous control group, and also had an interactive device in their seats. 250 participants (focus group (n:15) and control group (n:235)) in total were therefore able to use the device. It was announced by a speaker in the theatre before the performance started that specific seats were part of a research project for which the audience members in those seats would get instructions during the show, but in which they weren't obligated to participate. The speaker explained how to use the device, and noted that the answers would be displayed on the projection wall anonymously, that everyone in the theatre could follow in real time what the 250 participants were answering, and that the 250 participants could change their answers as many times as they

wanted within the given time frame. The device and its software didn't include a possibility for checking whether the answer was changed, but we did interview the participants about their experience of answering the questions.



**Figure 1.** A still frame of the design that dynamically displayed the 250 participants' answers on the projection wall in real time. This example is translated from Danish into: "To what degree do you experience that you yourself have a physical disability?" 1= not at all, 5 = to a certain degree, 10 = to a large degree.



**Figure 2.** The mobile device used for the engaging questionnaires. The device is developed by the company OMBEA, and the software and its usage were appropriated for this project. It was only possible to press numbers 1-10.

## Phenomenological Interview

Based on the IAT test and the answers given in the engaging questionnaires, we selected 7 participants, 4 women and 3 men, from the focus group of 15 to be interviewed (see figures 3 and 4). We used a specific type of qualitative interview, namely the phenomenological interview, which is a second-person semi-structured interview method with its own specific questioning and analysis techniques. The questioning techniques come from the interview method called the *Explicitation Interview* (Vermersch 1999, 2009; Petitmengin-Peugeot 1999; Petitmengin 2006; Petitmengin & Bitbol 2009; Bitbol & Petitmengin 2013), which uses open 'how' questions and specific strategies to draw the attention of the interviewees to detailed aspects of their experience. In our case, the focus was on how the 7 participants experienced Nossell on the stage, and what this theatre performance meant for their understanding of Nossell. The interview methodology won't be further described, but a full account of the methodological considerations and how they relate to cognitive science can be found in Høffding and Martiny (forthcoming)<sup>55</sup>.

The interviews were conducted in an interval of 2-4 weeks after the performance. The interviews lasted for around 1-1.5 hours and were structured around the IAT test and the participants' answers to the engaging questionnaires. The descriptions given by the 7 participants were structured and analyzed in accordance with

<sup>55</sup> See chapter 3 in this Ph.D. dissertation.

phenomenological methods of descriptive analysis (see Gallagher & Zahavi 2008, chapter 2), and the strategy of “phenomenological consistency” was employed in order to validate the descriptions (see Høffding and Martiny forthcoming).

Phenomenological consistency refers to both internal and external aspects of consistency, where internal phenomenological consistency refers to the ability to make comprehensible all the different participants’ descriptions found in the interviews. The more participants’ descriptions a certain phenomenological interpretation can make comprehensible, the deeper its internal phenomenological consistency. External phenomenological consistency refers to the ability of the overall account produced to work with and against already established theories of the phenomenon in question, namely the social understanding of physical disability. External phenomenological consistency is related to the methodological step of “intersubjective validation” (Varela & Shear 1999, 10) and “intersubjective corroboration” (Gallagher & Zahavi 2008, 29-31).

## 4. Results

This section presents the results of the IAT test, the engaging questionnaires, and the phenomenological interviews.

### 4.1 IAT test

In figure 3, the results of the IAT test can be seen for each participant in the focus group.

**Before the performance:** Strong (n=7), moderate (n=2), slight preference (n=2) for abled people compared to disabled people; little to no automatic preference between abled and disabled people (n=2); too many errors (n=1); missing (didn’t hand in the test) (n=1).

**After the performance:** Strong (n=5), moderate (n=4), a little to no automatic preference between abled and disabled people (n=2); too many errors (n=2); missing (didn’t hand in the test) (n=2).

<b>IAT Test</b>		
<b>Focus Group</b>	<b>Before</b>	<b>After</b>
PW, female, age 42	Strong pref. A	Little to no pref.
LA, male, age 40	Slight pref. A	Too many errors
LE, male, age 49	Missing	Missing
AK, female, age 48	Little to no pref.	Mod. pref. A
BI, female, age 39	Strong pref. A	Strong pref. A

BH, female, age 29	Mod. pref. A	Strong pref. A
GL, male, age 51	Too many errors	Too many errors
GO, female, age 52	Mod. pref. A	Missing
MM, female, age 31	Little to no pref.	Little to no pref.
LM, female, age 24	Strong pref. A	Mod. pref. A
AL, female, age 22	Strong pref. A	Mod. pref. A
SD, male, age 60	Strong pref. A	Strong pref. A
MB, male, age 23	Strong pref. A	Strong pref. A
AN, male, age 31	Slight pref. A	Mod. pref. A
JO, male, age 59	Strong pref. A	Strong pref. A

**Figure 3:** The results of the IAT test; the 7 participants in white were interviewed.

## 4.2. Engaging Questionnaire

In figure 4, the results of the engaging questionnaire can be seen for each participant in the focus group, except for one participant (LM), who didn't participate, since the device in her chair was missing. In figure 4, the results for the control group can also be seen; they are illustrated as an average of the responses for each question, and there were an average of 204.2 responses out of 235 possible ones.

	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4
<b>Focus Group</b>	10 = large degree 1 = not at all	10 = large degree 1 = not at all	10 = large degree 1 = not at all	10 = much better 1 = much worse	10 = much more, 1 = much less	10 = large degree 1 = not at all	10 = much more, 1 = much less	10 = much better 1 = much worse	10 = much more, 1 = much less	10 = much more, 1 = much less	10 = much more, 1 = much less	10 = much more, 1 = much less	10 = large degree 1 = not at all	10 = large degree 1 = not at all	10 = large degree 1 = not at all	10 = much more, 1 = much less
PW (F) age 42	1	3	3	6	6	9	10	3	7	5	3	5	1	10	10	3
LA (M) age 40	1	4	4	10	8	10	7	5	5	5	2	5	2	8	10	3
LE (M) age 49	1	5	2	10	6	10	8	2	10	5	5	5	2	10	7	8
AK (F) age 48	5	3	3	9	6	9	9	2	7	6	4	5	5	10	9	5
BI (F) age 39	3	4	6	6	2	-	10	5	5	1	5	5	3	5	5	-
BH (F) age 29	1	3	8	10	5	10	10	2	6	5	7	5	2	5	10	6
GL (M) age 51	1	5	1	10	9	10	8	2	10	8	5	6	1	5	5	5
GO (F) age 52	1	5	5	10	5	9	10	2	5	5	5	5	1	7	10	5
MM (F) age 31	1	6	4	8	6	10	10	2	4	3	5	5	2	1	10	5
LM (F) age 24	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

AL (F) age 22	1	1	1	10	6	10	10	2	8	9	2	5	2	10	5	1
SD (M) age 60	4	5	10	10	1	10	10	4	5	5	10	5	1	10	5	5
MB (M) age 23	1	4	5	10	5	10	10	4	7	5	6	4	1	10	7	5
AN (M) age 31	6	7	5	7	-	10	10	5	4	4	7	3	7	10	10	4
JO (M) age 59	1	7	4	10	6	9	9	3	6	7	3	4	1	1	10	6
<b>Average response</b>	<b>2,00</b>	<b>4,43</b>	<b>4,36</b>	<b>9,00</b>	<b>5,07</b>	<b>9,00</b>	<b>9,36</b>	<b>3,07</b>	<b>6,36</b>	<b>5,21</b>	<b>4,93</b>	<b>4,79</b>	<b>2,21</b>	<b>7,29</b>	<b>8,07</b>	<b>4,36</b>
<b>Control group</b>																
Number of responses	202	208	199	207	205	204	206	208	206	203	205	207	205	199	203	200
<b>Average response</b>	<b>2,32</b>	<b>5,49</b>	<b>5,73</b>	<b>8,49</b>	<b>4,88</b>	<b>9,34</b>	<b>9,02</b>	<b>3,30</b>	<b>6,10</b>	<b>5,76</b>	<b>6,05</b>	<b>4,63</b>	<b>2,92</b>	<b>7,25</b>	<b>8,40</b>	<b>4,56</b>

### Questions

- 1.1: To what degree do you experience that you yourself have a physical disability?
- 1.2: To what degree are you able to familiarize yourself with how it is to live with a physical disability?
- 1.3: To what degree is a person with CP normal?
- 2.1: Where would you place your quality of life relative to Jacob's?
- 2.2: How exhausting is it to experience Jacob on stage?
- 2.3: To what degree do you think Jacob notices how others feel about being with him?
- 2.4: If you spoke like Jacob, how aware would you be of your speech?
- 2.5: Where do you believe that Jacob would place his quality of life relative to yours?
- 3.1: Do you think Jacob is more hurt by being rejected by someone than you are?
- 3.2: If you had sex with a person with the same conditions as Jacob, do you think this person would be more uncertain about the situation than you?
- 3.3: Do you have a more settled relation to your own body than Jacob?
- 3.4: Do you think you have a more realistic self-image than Jacob?
- 4.1: If you were to have a child, to what degree would you want to have the child with Jacob or a woman with the same conditions?
- 4.2: If you were to choose a sperm donor, to what degree would you disregard a person with CP?
- 4.3: If Jacob was your father, to what degree do you think you would have had a good upbringing?
- 4.4: Are you more capable of having a child with CP than Jacob?

**Figure 4. a)** The results of and average response to the engaging questionnaire of both the focus and control group; the 7 participants in white were interviewed. **b)** The questions asked in the questionnaire.

### 4.3. Phenomenological Interviews

The interviews started by asking the 7 participants about their experience of taking the IAT test before and after the performance and about their impression of the results. The participants that acquired a 'strong preference for abled people' before and/or after the performance described that they were surprised, since they did not experience themselves as preferring abled persons. They rather described themselves as being open-minded, having sympathy for both abled and disabled people. However, as the interviews continued, all the participants did describe how the initial encounter with Nossell was one of pity and of feeling sorry for him. AK gave the following description of her encounter with Nossell:

"It's just something about it being unfamiliar, a bit scary perhaps, it's unpleasant to watch, you are afraid that perhaps the person is suffering, that the person experiences pain... You are of course confronted with a human being that in some way, you believe, is locked in his own body, and you feel sorry for them."

"You are brought up to help people who have it difficult and it would be rude not to. You get uncomfortable when you see someone who has problems and you believe that it's a problem. What if they fall? So you better help them...It's a bit like when you ignore someone who is sitting and begging or something. You should really give him some money. He's sitting right there and you have seen him...You feel it unpleasant to do so, and that's how I feel, unpleasant, if there is a disabled person trying [for example] to get down the stairs."

AK emphasizes verbal communication as crucial for her social engagement, and explains that this was a problem in her initial encounter with Nossell, since he has a speech impediment. The other participants also emphasized the difficulty of understanding Nossell. JO relates this difficulty to his initial encounter with Nossell in the following way:

"One aspect is our speech and when it's not quite as you would expect from people, then you have an instant impression. The second aspect is that, if your body language doesn't match, then you have two parts of your communication already ruined."

"[Communicating with persons with CP] will be something that takes up a lot of the concentration you have. You get sidetracked when something happens all the time in one's field of vision. Everybody knows that. If we talk to children where it's full speed ahead, that's rough. You have the same if people have uncontrolled movements, because is it a part of the speech or is it an uncontrolled movement? You first of all have to include that in your decoder."

For PW, this communication difficulty led to a feeling of embarrassment: "It's simply not good enough that you can't understand what he says and you feel a little embarrassed, because it seems rude not to be able



to understand what he says.” AL also describes how her experience of pity in encountering Nossell is related to a lack of understanding:

“The problem is that I pity the person, and then, I think, I destroy the entire balance system between people...I don’t know if I should compensate for it or accept it or how I should deal with this, because I don’t know how he feels. I can’t put myself in his place.”

The participants describe their lack of understanding Nossell as an issue of not being able to put themselves in his shoes. JO describes it in the following way:

“[In the encounter] you’ve just been made aware that it’s a completely different world. It’s perhaps empathy, but [regardless of what type of experience it is] it’s at least an experience. In the sense that I have difficulties putting myself in the position of not being able to control my pronunciation or control my body...I can’t feel that. I can’t put myself so much out of my own system, that I will understand it. I understand there is a difference.”

MB clarifies the difficulties of understanding persons with CP by saying that:

“Logically I can put myself in the position that it must be hard, but I don’t think that you can really put yourself in their shoes if you haven’t tried it...I’ve had some injuries, but it’s not at all the same. With my heart or feelings I can’t put myself in their position, but logically I can imagine that it must be very difficult and terrible in many ways.”

All the participants described that, as the theatre performance progressed, and they were asked to answer the different questions using the engaging questionnaire system, they were influenced by different experiences, but they didn’t change their initial answers. Having given an answer to question 2.1 about one’s own life quality that was below the average, BI explains that she probably “had gotten sympathy for Jacob and then graded myself lower. I think that’s what happened, without it being a conscious choice.” AK also describes the experience of seeing the other answers on the projection wall as influential:

“No I didn’t change my answers, but sometimes you were aware of what you knew you probably should have answered, but you answered a little different and you had to stand by that answer. There are some answers that are politically correct answers...and there were a few times where I thought that my answers were way off, but that’s just how I feel.”

MB further elaborates on the experience of having to answer together in real time with so many other people:

“It was interesting to be a part of because you could see [the answers] immediately, in the sense that they came up on the screen. So I felt like I was part of a social experiment. It was a good way to get an overview and the most interesting was when people had answered before it came up on the screen. There were some questions where it went up to 90% immediately, because people had already pressed the button and were very sure of their answer. I think that they were the most interesting questions, rather than those where it was evenly distributed, because here you could really see that among us ordinary [people], whom we were representing, that is the general population, we have a clear feeling about that question.”

However, all the participants describe how the questions and the way they were shown became a way for them to develop their thoughts on the different issues. LA describes that the questions

“put different thoughts in my head during the performance. It was like being compelled to think about different things, relate to different things, and in that way I really think the questions followed the performance well. You were constantly guided forward. Then came a new question and then one was guided on to something new, and was forced to relate to it.”

When the participants were asked about their participation in this experiment and the theatre performance, they unanimously described how it changed their understanding of Nossell. They described it in many different ways: 1) the performance revealed other more emotional sides of Nossell than just his physical disability and therefore presented a more whole and unique picture of the person, 2) the encounter with Nossell offered an experience of the person behind the physical disability and, in getting to know him, the real person came into the foreground, and the disability fell into the background, and 3) the performance provided an experience of empathy that was necessary in order to put themselves in his shoes. For LA, the change was generally “about attending less to the disability and less to the challenges, and more to the person. It’s a little cliché...but it changes your entire web of engagement with the person.”

AK describes that the reason why her understanding of Nossell changed was that “you are moved, you are touched, in a different way than if you were to read about it in the newspaper.” LA elaborates on this by saying that it was the moving experience of Nossell’s performance that constituted the change:

“When the performance began, I felt sorry for him and that definitely changed. Of course I don’t think it’s great that he has the challenges he has, but on the other hand, I experienced that he can do a lot of things and he does a lot of things. And the respect I got, you could say, has probably just as much to do with the fact that he does some things with his life despite the challenges he has. It’s remarkable and we could probably all learn something from this... When I meet people who have an obvious disability, I inevitably think of the theater performance. I have thought about it several times afterwards. It’s interesting how [the performance] just pops up in my head.”

## 5. Discussion

The specific question we wanted to address in the experiment was: “*Can theatre be used for a second-person investigation of social understanding of persons with physical disabilities?*” In the following we will discuss the question in relation the three different methods (IAT test, engaging questionnaires, and phenomenological interview) we used to understand the focus group’s experience of Nossell.

### 5.1. Indirect and Direct Measures of Social understanding

In social psychology, measuring the attitudes toward persons with disability has usually been divided into direct or indirect measurements. Direct measures are said to rely on controlled and conscious processes (Beer et al. 2008), which are typically based on asking people to verbally and reflectively self-report or describe their answer to a specific question. Questionnaires are widely used in social psychology, as in opinion surveys, since they allow for a large amount of quantifiable data to be collected in a timely manner. This was also the case in this theatre experiment, where we used engaging questionnaires to dynamically collect in real time answers from an average of 218 out of 250 possible people (focus group (n: 14) and control (n: 204.2)).

Looking at the results from the questionnaires, the averages of the focus and control groups reflect each other nicely with only a few exceptions. These results can be corroborated with data from the large scale study done on the Danish social perception of disabled people (Olsen 2000), which overall highlights that, when people are asked more general questions about disabled people, their answers are generally positive. However, when the questions are specific, e.g., when they are about a certain disability and in relation to a specific context, they are more negative. For example, only 2% of 1029 Danes had a positive attitude regarding a disabled person’s ability to be a parent, whereas 24% had a slightly negative attitude, 36% a moderately negative attitude and 11% a strongly negative attitude. Specifically in relation to CP, 24% of 1032 Danes wanted to proceed with a hypothetical pregnancy if they knew their child would have CP, while 30% would definitely and 24% would probably terminate the pregnancy.

This change in attitude was also seen in the engaging questionnaire, where the average answer to the general question, “to what degree is a person with CP normal?” was somewhat positive: 4.36 for the focus group and 5.73 for the control group, where 5 corresponds to ‘to some degree’. However, when they were asked the questions, “If you were to have a child, to what degree would you want to have the child with Jacob or a woman with the same conditions?” and “If you were to choose a sperm donor, to what degree would you disregard a person with CP?” the answers were largely negative for both the focus and control groups. Interestingly, when asked the two last questions, “If Jacob was your father, to what degree do you think you would have had a good upbringing?” and “Are you more capable of having a child with CP than Jacob?” the answers were largely positive for both the focus and control groups

The aim here is not to argue whether or not the results are justified, but to question whether they say anything about the participants' social and engaged understanding of experiencing the theatre performance. One argument could be that the fact that the participants' answers became more positive throughout the course of the performance indicates such engagement with Nossell. However, based on these results alone, it's not possible to come to any such conclusion.

Even if we could draw such a conclusion, the use of direct measures of social cognition has been criticized for being vulnerable to socially desirable responses (Greenwald et al. 2009) and for possibly being inaccurate. We don't always have, as it has been famously argued by Nisbett and Wilson (1977), direct and accurate conscious access to the cognitive processes involved in, for example, self-reporting, evaluation and judgment. When we interviewed the participants about their experience of answering the questionnaire, they stated that they weren't influenced by the 'politically correct' answers or the socially 'desirable' opinions in the theatre. They did, nonetheless, acknowledge that the setting in some way created a sympathetic and social experience that framed their answers to the questions.

Indirect measures, such as the IAT test, are a way to avoid socially desirable responses and reveal associations not consciously accessible to and controlled by the participant (Greenwald & Banaji 1995; Greenwald et al. 1998). Implicit association techniques used in the IAT test are supposed to activate unconscious and automatic cognitive processes, since the responses are provided within milliseconds of stimuli presentation (Beer et al. 2008; Fazio & Olson 2003; Greenwald et al. 2003). This means that the IAT test may be a better and more unbiased way of investigating the engaged understanding of Nossell.

If we look at the results of the IAT test in our social theatre experiment, about half of the participants (7 out of 15) expressed a 'strong preference for abled people' before the performance, which means that their response difference between pairings demonstrated a strong association between disabled/unpleasant and abled/pleasant. In other words, the response in pairing disabled with pleasant valence took a lot longer than pairing abled with pleasant valence, and it was faster the other way around. Studies show that the strong preference is the most common preference in relation to physical disability (Greenwald et al. 2003). This general result corroborates to a certain degree with the descriptions that the participants gave of their initial and immediate experience of encountering Nossell. They felt the experience was unpleasant, felt sorry for him, felt pity and embarrassment when they couldn't understand what he said, and overall felt they couldn't put themselves in his shoes. However, no clear connection between the individual IAT results and the degree of unpleasantness is seen in either the questionnaires or the interviews.

What does this say about the participants' understanding of Nossell in experiencing the theatre performance? One could argue that, since the understanding of Nossell went from 'pity to respect', as the participants described in interviews, the IAT test should have changed after the performance. However, when we look at the results of the IAT test after the theatre performance, there are no systematic changes in one

way or the other, e.g., going from a ‘strong preference’ to a ‘moderate preference’. It may seem as though there is a slight decrease in the number of subjects with a strong preference for abled people; however, the individuals were seen to move down as well as up the scale and, in light of the small amount of data, no real direction is detectable. Vaughn et al. (2011) have further pointed out that one may experience a possible learning effect in taking the IAT test more than once, but there were also no signs of such an effect.

From an EC and second-person study of social cognition, the IAT tests are, however, problematic, since they presuppose and target ‘automatic’ and ‘implicit’ mental associations that operate without awareness, intention and control. Such a traditional understanding of cognition is precisely what EC and the interactive turn in social cognition are arguing against. The main idea is that engaged social understanding includes experiential, emotional and reciprocal aspects of cognition that are neither the focus of what the IAT test measures nor, perhaps, even possible to measure. One of the reasons why this is the case is that, as pointed out by Satne and Ropestorff, engaged understanding is an experience of the other in which one commits to the other as a person (Satne & Ropestorff 2015). In the IAT test, however, one is supposed to understand the person through signs and words on a computer screen, but these don’t represent the person with disability: they represent, rather, the concept of ‘disability’.

## 5.2. An Engaged and Transformed Understanding of Physical Disability

If we focus specifically on the results of the phenomenological interviews, the participants all described the experience of pity in encountering Nossell and the difficulty of understanding him. However, as the performance progressed, they described being experientially and emotionally moved, which transformed their understanding of Nossell. They were able to see him as a person, rather than as a *disabled* person, which changed their engaged understanding of him. For some of the participants, this in fact influenced their daily lives, insofar as the performance and Nossell reappeared to them when perceiving others with physical disability.

The aim here is not to argue that the results from phenomenological interviews with 7 participants represent the focus group, control group or the entire audience as such. Also, we only interviewed the participants two weeks after the performance, so the aim is not to discuss whether the effectual transformation in understanding Nossell will be long-term. The aim is to understand what initiated the experience of engaging with Nossell in the theatre so as to provide strategies for cultivating this kind of collaboration between social cognition and theatre, and for developing predictions for future research in such second-person studies of social cognition.

The first promising aspect is the use of the engaging questionnaire. While there might be problematic aspects in using such direct measurement, the participants described that the strategy of making the

questionnaires interactive, real-time and dynamic, such that the audience could see what both the focus and control groups were answering, influenced the development of their engaged understanding of Nossell. There are some interesting features of using questionnaires in this way, since, as the participants described in the interview, it creates a social experience of how their answers relate to everyone else's. With further development, we suspect that engaging questionnaires can be used for providing answers to social questions in the setting of sharing a social and engaged experience of, for example, being part of a group. Although engagement is the advantage of this form of questionnaire, it's also its disadvantage, since the development in understanding from the beginning to the end of the questionnaire makes it difficult to work with the results. For further projects, one could, which we didn't do, try to include a semantic differential scale or a Likert scale in developing the engaging questions. It requires further investigation to determine which scale is most beneficial for engaging questionnaires.

The aim here is not to argue that engaging questionnaires are sufficient in themselves to investigate the engaged and transformed understanding of Nossell that happened in the theatre performance. One reason why the IAT test was developed was that conscious self-reports can be socially biased and possibly inaccurate, which is also a possibility in our project. However, we are going to argue that it's in combining engaging questionnaires with phenomenological interviews that the questionnaire becomes both an interesting way of acquiring data on engaged understanding and a technique to ensure that such engaged understanding takes place.

In respect to questionnaires, the term 'consciousness', which is used in conscious self-reports, refers to reflective self-awareness, where we for example introspect so as to evaluate or judge something, e.g., Nossell. The main reason for developing the phenomenological interview is to emphasize that the interview is a science in and of itself, which, when done properly, can avoid the critiques typically raised against introspective self-reports. There are many reasons why this is the case (see Høffding and Martiny forthcoming; Petimengin 2006; Petimengin et al. 2013 for a more extensive discussion) but, here, we will highlight two especially important aspects of the phenomenological interview, namely 'pre-reflective experience' and 'phenomenological validity.'

The first aspect is that, in the phenomenological interview, the aim is not specifically to understand the reflective and cognitive aspects of self-reports, but to understand the conscious experience at the pre-reflective level. In order to reach this level, the aim in the interview is to guide the interviewees to describe experiences that, at the moment they were experiencing them, were non-observational and non-conceptual and were related to bodily, situational and emotional aspects of experience. The way that the interviewee describes these pre-reflective experiences is of course through reflective means of remembering, conceptualizing and verbalizing the experiences. However, in contrast to understanding the relation between

the experience and its description as a question of corresponding truth, the phenomenological interview relies on phenomenological validation.

Such validity emphasizes the technique of performing the interview, which is understood as a second-person engagement with the interviewee, and the pragmatics of doing the descriptive phenomenological analysis, which is accomplished by using internal and external consistency. The latter is especially interesting for this social experiment, since it emphasizes the importance of corroboration with other data on the same phenomenon and the possible use of multiple methods in studying the phenomenon. We have tried to do this in our social experiment, both by corroborating our results with data from other IAT tests and questionnaires on the same social phenomenon, and by using both the IAT test, engaging questionnaires, and phenomenological interviews to study the social experience of physical disability.

In fact, the phenomenological interview was originally framed in cognitive science in relation to Varela's method of 'neuro-phenomenology,' where the idea was to combine qualitative (first-person) data from interviews with quantitative (third-person) data from e.g. neurological scanning (Varela 1996). Even though we have been critical of the use of the IAT test in this social experiment, we see possibilities in using the engaging questionnaire to corroborate data from the phenomenological interview. Such fruitful combination requires further development but, in that respect, one might include other quantitative (third-person) measurements than the IAT-test. For example, studies of astronauts' experience of having been in space, conducted by Gallagher and colleagues, have taken up the same strategy of multiple methods, where phenomenological interviews and questionnaires are part of the methods (Reinerman-Jones et al. 2013, Bockelman et al. 2013, Gallagher et al. 2014). In addition to such methods, they use physiological measures, such as electroencephalogram (EEG), electrocardiogram (ECG), and Covidien's fNIR system, which records the oxygenation of haemoglobin in the frontal lobe. The use of such measurements is one promising way of including further third-person data and developing the social experiment of using theatre for understanding social engagement.

Another way to develop the combination of social cognition and theatre is to set up an experiment in which a focus group experiences a live theater performance, and a control group of the same size, in the same theatre, with the same number of audience members and the same engaging questionnaire, observes a video recording of the theatre performance so as to remove the engaged independent variable of the experiment. How such and other possible ways of encouraging the creative collaboration between social cognitive science and theatre performance will turn out is, however, open for further development.

## 6. Conclusion

In this paper, we have tried to argue that it is in fact possible to use theatre performance as part of a second-person study of social cognition. We have done so by presenting and discussing a specific social theatre experiment, where theatre performance was part of the investigation of the social understanding of persons with physical disabilities. We argued that the audience's embodied and engaged experience in the theatre performance can be seen as the experiment's independent variables, and we pointed to future directions in which this combination of social cognition and theatre performance can develop by highlighting the use of engaging questionnaires and phenomenological interviews in investigating the dependent variables.

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## Chapter 10

### Open Mind means Open Media

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# Open Mind means Open Media

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## Abstract

The challenges of *collaboration*, *communication*, and *cultivation* prevent the Open Science (OS) movement from progressing. We argue that open access is not in itself a sufficient solution for overcoming these three challenges and present the concept of *Open Media* as a way to do science through different media and formats. We discuss, using ‘open minded’ and embodied cognitive science, two cases where we experiment with open media in the collaboration between science and documentary. We argue for different advantages of using documentary to face the challenge of collaboration, such as in preserving audio-visual data in science, establishing a medium for interdisciplinary engagement and revealing contextualized, tacit and dynamic knowledge. Documentary also has advantages for science communication, since it uses language that can reach beyond academia, so as to engage society in science and science in society. To cultivate the idea of open media depends on further development, but we argue that with it follows an understanding of scientific evaluation and validation as more dynamic and open-ended.

## 1. Open Science: What, Why and How

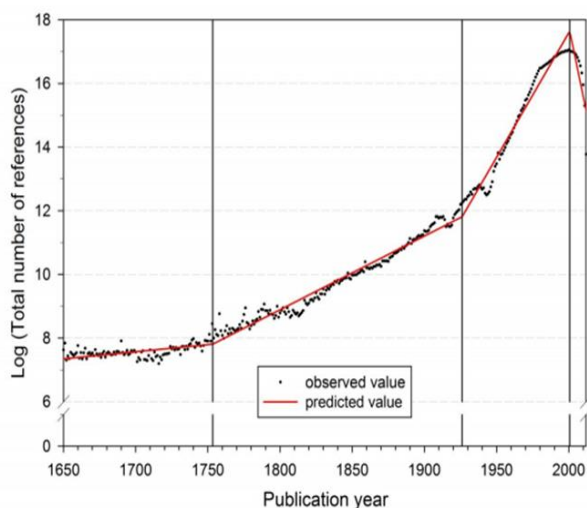
Opening up science has become an important mission for many contemporary scientists, and Open Science (OS) is slowly, but, increasingly developing into an influential science movement. The concept of ‘open’ should be understood as opening up, as early as it’s practically possible, for all the kinds of scientific knowledge in the research process (Nielsen 2011). At the moment, this means opening up: 1) the method (*Open Methodology*), 2) the software (*Open Source*), 3) the datasets (*Open Data*), 4) the reviewing process (*Open Peer Review*), 5) the publication (*Open Access*) and 6) the teaching (*Open Educational Resources*) (Watson 2015; see also OpenScience ASAP; Kraker et al. 2011). The knowledge of these aspects is open if anyone is free to access, use, modify, and share it for any purpose, which is subject, at most, to requirements that it preserves provenance and openness ([Open Definition](#)).

### 1.1. Does Open Science Mean Better Science?

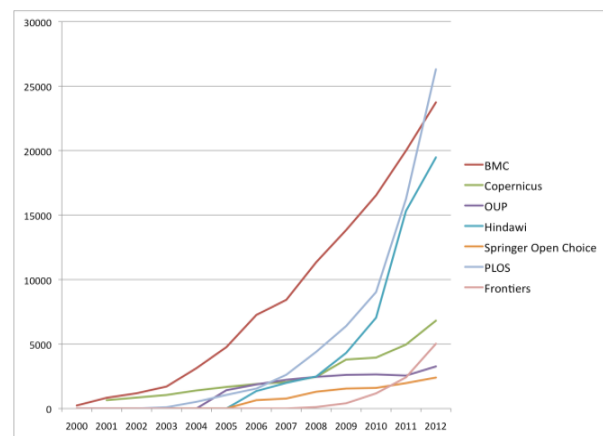
Many supporters of OS (e.g. Molloy 2011) typically adopt a strong claim: ‘Open science means better science.’ As a positive argument for this claim it is stated that through the ‘wisdom of the crowd’ we can know far more than possible for an individual scientist and so it broadens the range of problems that can be solved. The internet and online tools are seen as the shared communicative space in which this amplification of collective intelligence can happen. For OS they are cognitive tools that have completely reinvented the

way in which scientists collaborate to create knowledge (Nielsen 2012). Many positive examples are presented in the OS literature to support this, such as Foldit, InnoCentive, FriendFeed, ArXiv, SPIRES, the Polymath Project, GenBank, and Galaxy Zoo. Examples like these, in combination with an increased societal focus on grand challenges, lend themselves to a strong positive support of OS.

Collaboration has become the talk of the town, even for the current scientific community (Adams 2013), but negative examples of inherent problems within this community is presented by OS as an *ex negative* argument for their strong claim. For example, scientific knowledge tends to be exaggerated and inflated in the current system, due to the economic landscape of publications (Young et al., 2008), and publication retractions have increased 1.200 % over the past decade (van Noorden 2011). The peer reviewing process is slow, stifles innovation, and lacks transparency (Smith 2010). Necessary methodological information and datasets are typically not included in the publications, making reproducibility of results problematic (Knorr-Cetina 1981). Exponential growth of publications (see figure 1 and 2) creates an overload of information, contributing to simultaneous and repeated discoveries and ‘invisible colleges’ (Price, 1963).



**Figure 1:** Segmented growth of the annual number of cited references from 1650 to 2012 (citing publications from 1980 to 2012) (Bornemann & Mutz 2014)



**Figure 2:** Data on publication volumes for major Open Access publishers (Neylon 2013).

Despite the many arguments supporting OS, the claim that open science is better science is too strong. The human factor is difficult for OS to factor in, since there are many counterproductive examples where the crowd using online tools is not wise. Opening up for the research processes doesn't automatically lead to

better scientific knowledge. There should be, as stated by Gieryn, a distinction between “real science [from] pseudoscience, amateur science, deviant or fraudulent science, bad science, junk science, popular science” (1999, 17). However, in this respect we should not be talking about ‘open’ and ‘closed’ science, ‘better’ and ‘worse’ science, or about a new ‘movement’ of science. In OS we should overall be focused on (good) science (Watson 2015).

## 1.2 Three Challenges

How can OS harness the potential of the open without ‘openwashing’ the necessary conditions for knowledge? There are currently three fundamental challenges that prevent the OS ship from taking off:

1. **The Challenge of Collaboration:** OS requires scientists that are both willing and able to collaborate using online tools. The current science landscape and education don’t provide any incentives or skills for such research practice.
2. **The Challenge of Communication:** The current ‘publish or perish’ incentives overemphasize publication in conventional journals, which counterproductively eliminates the motivation for utilizing and appropriating means of science communication through more modern media.
3. **The Challenge of Cultivation:** As with the adaptation of the journal publication, it requires a cultural change in order for the internet and online tools to be appropriated into the knowledge processes of science. This change requires an overall reformation of how to do science.

## 1.3. Open Access isn’t a Sufficient Solution

One influential attempt to overcome the three challenges above has been done by the Open Access movement (see the Budapest Open Access Initiative), where the Public Library of Science (PLOS ONE), is the movement’s most prominent advocate. PLOS ONE was established as a way to overcome the publishers’ paywall and academia’s obsession with journal status and impact factors. The aim was to make a journal where taxpayers who already paid for the research wouldn’t have to pay again to read the results (Eisen 2012) and where articles are not the end result, but the beginning of further discussion (MacCallum 2006; Giles 2007). Today, almost 10 years after its launch, PLOS ONE is not only the largest open access journal (see figure 2), but, by number of papers published, the largest journal in general.

PLOS ONE has had immense success, and played an influential role in the open access focus that is now an integral part of academia. One of the problems with the open access movement is, nevertheless, that it preserves a conservative approach to science. Science is in a Kuhnian way seen as equivalent to an increase

of knowledge specialization (Kuhn 2000). Scientists aim to develop more and more specialized terminologies, methods, tools, data, discussions and theories, and communicating through journal publications is appropriate for this development. Familiarity with the specialized terminologies, methods, tools, data, discussions and theories are taken for granted and scientists outside a specific discipline have difficulties understanding what is published. Even scientists within the same discipline may have problems understanding what their colleagues are publishing. For the rest of society it's almost impossible to understand. Publishing open access doesn't solve the communication challenge, since the knowledge now openly published, is understandable still only for a few.

For Kuhn, limits in communication is a condition of the specialization of science (Kuhn 2000), but the aim of communicating knowledge should be, and have always been, such that others can engage with it (see introducing remarks in the first journal from 1665, *Philosophical Transactions*, (Oldenburg 1665)). Communicate means 'to share' (from Latin *commūnicāre*) and in this respect it's worth mentioning that PLOS ONE applies the Creative Commons Attribution (CC BY) license to their publications. Here sharing, in the 4.0 version, is defined as: "copy and redistribute the material in *any medium or format*" (<https://creativecommons.org/licenses/by/4.0/>). We are going to approach this communication challenge, along with the two other OS challenges presented above, by taking this definition of 'sharing' literally.

## 2. Opening Up the Medium

We will present a proof-of-concept for doing science in different media and formats than journal publication. We call this *Open Media: opening up of the medium through which scientific knowledge processes can be done and scientific contributions can be communicated*.

Open Media is not a question of abandoning the written medium and the format of the journal, but a question of using other media types to supplement it. This has already been seen in a few cases, such as with Journal of Visualized Experiments (JOVE), where scientists upload videos of how their experiments work, or in the famous Foldit example, where experimental research on protein folding uses virtual interaction and gamification (Copper et al. 2010).

The difficulty is how one should evaluate and further develop the idea of Open Media. It requires, first of all, a cultural shift in how science is done, which Nielsen has called *Extreme Openness* (Nielsen 2012, 183). However, as we have argued above, openness, extreme or not, doesn't automatically lead to better scientific knowledge. For us it's instead a question of being *Open-Minded* scientists.



## 2.1 Open-Minded Science

OS is a meta-science, i.e. a science about how to do science, and it lacks a scientific foundation for evaluating what it means to open up the knowledge processes of science. In this respect cognitive science is a relevant method, since it's a science of the mind, and therefore also a science of the mind of open scientists. Cognitive science by itself cannot give a comprehensive understanding of all aspects of how to do open science, but it can give important insights into the cognitive processes of generating knowledge, which is a crucial part of any science.

The cross-fertilization between cognitive science and OS is promising, and studies in cognitive science of 'collective, group and collaborative intelligence', 'crowd and group behavior', and 'group and collective decision-making' have already been an influential inspiration for OS. The defining authority in current cognitive science is also much in line with the aim of opening up. This authority is called *Embodied, Embedded, Enacted and Extended Cognition (EC)*, which criticizes traditional cognitive science for reading cognition in mental terms and situating it within the skull. In contrast, EC holds different fundamental claims, which stress that cognition is something experiential and emotional that we enact in the world, together with others and through the use of technology (Varela et al. 1991; Clark 1997, 2008; Wilson 2002; Noë 2004; Gallagher 2005; Thompson 2007, 2014; Gallagher & Zahavi 2008; Chemero 2009; Rowlands 2010). Thus, EC seems a fitting theoretical foundation and method for OS.

Recently there has been an attempt to cross-fertilize cognitive science and OS, which is called the Open MIND Project (<http://open-mind.net/about>). As a point of departure the Open MIND project is an exercise in editorial open mindedness and an experiment in open access publishing, which we already have argued is problematic. Relevant for our purpose is, nevertheless, Metzinger and Windt's editorial paper, where they clarify what is meant by open mindedness (Metzinger & Windt 2015).

First of all, being open minded should not be understood as a theoretical position, but as an epistemic practice and attitude for approaching ideas, topics, theories, methods, and fellow researchers. It's characterized by 1) epistemic humility, 2) intellectual honesty and 3) charity (Metzinger & Windt 2015, 2), which taken together highlight a pragmatic dimension of doing cognitive science: there should be no single and right way to do research, and the aim should be to ask better questions, to question or reject prior commitments, to see ambiguity and the possibility of falsification as indicators of great scientific process, and to promote new and sustainable forms of collaboration. To embrace these three aspects is not to become an 'everything goes' scientist, but having an open mind in academia is about the emergence of a new type of scientist.

Ideally the epistemic practice of open mindedness should provide strategies for cultivating collaboration and should develop predictions for future research. The real task of providing such strategies and predictions is to creatively test new types of collaboration, which means to deliver

“a new understanding of progress, of acceptable forms of inquiry and methods, as well as new measures of success, for instance concerning novel forms of collaboration and publication formats that are still under the radar of institutionalized impact factors” (Metzinger & Windt 2015, 23).

It's with open minds that we will discuss the idea of open media and test a new type of collaboration.

## 2.2 Science and Documentary: A Collaborative Experiment

Documenting qua filming, an audio-visual medium, has been used in many different scientific disciplines such as ethnography, anthropology, psychology, and educational and social sciences. So, instead of 'reinventing the wheel,' we turn to the use of documentary as a preliminary source of inspiration for open media. To focus on documentary is not to argue that open media should be restricted to the use of documentary, but it's a way to start opening up this new way of doing science.

As a point of departure we, in collaboration with Danish Film Institute, Creative Europe Media Desk Denmark and the production company Final Cut 4 Real, organized a workshop for fifty of relevant and established scientists, documentary directors and producers in the Danish science and documentary community. The purpose of the workshop was, among other things, to discuss the possibilities of a collaborative methodology between science and documentary.

During the workshop we interviewed a number of scientists (L. Oxenløwe, Professor in photonics, D. Pedersen, Associated Professor in philosophy, A. Roepstorff, Professor in anthropology, and B. Møller, Professor in synthetic biology), and documentarists (P. Ambo, director of *Free the Mind*, J. Metz, director of *Armadillo*, and J. Oppenheimer director of *The Act of Killing*) about this possible collaboration. The full interviews can be seen here ([collaborativesociety.org](http://collaborativesociety.org)) and a summary of the interviews can be seen here ([scienceXcinema](http://scienceXcinema)). The overall points of the interviews were:

- 1) Scientists have concerns about how their work is communicated through news, entertainment or mass media.
- 2) Documentary is not the same as news, entertainment or mass media.
- 3) In some cases there are more parallels and similarities than differences between the way that scientists and documentarists work.
- 4) The difficulty of collaborating between the two is to see documentary as a part of the research process and not just communicating a research result.

Following this point of departure we set up two experiments to test whether it's possible to use documentary as part of the research process.

### 3. Natural Disorder: Understanding Cerebral Palsy

The first experiment is the documentary film called *Natural Disorder*, by director Christian Sønderby Jepsen. The film is a story about Jacob Nossell, who lives with cerebral palsy (CP). CP is a group of disorders in the development of postural and motor control, occurring as a result of a non-progressive lesion in the developing central nervous system (Bax et al. 2005). CP is the most common type of disorder associated with congenital motor impairment (Aisen et al. 2011), but at the same time, it's a heterogeneous and complex condition that varies according to the particular brain lesion and individual in question.

The documentary wants to address the complexity of living with CP, by following Nossell, in a quest for understanding what it means from his first-person perspective to live with CP and by communicating his perspective in a narrative that is understandable for others. The film will premiere in Denmark 7<sup>th</sup> October 2015.

However, the documentary was also an experiment operating with two hypotheses: 1) documentary is a way *to do* collaborative science that acknowledges the complexity of living with CP, and 2) documentary is a way to communicate this complexity of living with CP. This means that the experiment both deals with the challenge of collaboration and communication, and shows the intrinsic interrelation between the two.

#### 3.1 How to Collaborate: Interdisciplinary Engagement

The WHO, following ICF, have promoted a “bio-psycho-social model” that understands disability as a dynamic and complex interaction between health (biological) conditions, personal (psychological) and environmental (social) factors (WHO 2011, ICF 2001). To perform such ‘bio-psycho-social’ diagnosis, treatment or habilitation should be the ideal aim for CP, so as to address the ‘whole,’ ‘unique,’ and ‘individual’ person living with CP. To do so would require collaboration between scientists and professionals from disciplines such as neurology, pediatrics, psychology, physiotherapy, occupational therapy, pedagogy and educational sociology. Interdisciplinary collaboration on such a large scale is problematic, since the different scientists and professionals use different specialized terminologies, methods and tools, and ultimately have different fundamentals for diagnosing, treating and habilitating CP.

Roschelle and Teasley (1995) have famously distinguished ‘cooperative’ from ‘collaborative’ problem solving, by distinguishing between a group of individuals solving distinct portions of a problem and individuals collectively solving the problem together. The latter should be understood as a collaborative process and an activity of continued attempt and mutual engagement between individuals, who share an

emergent, socially-negotiated set of knowledge elements. These elements constitute what Teasley and Rochelle calls a Joint Problem Space (JPS), which is a “negotiated and shared conceptual space, constructed through the external mediational framework of shared language, situation and activity – not merely *inside* the cognitive contents of each individual’s head” (Roschelle and Teasley 1995, 71).

This means that in an interdisciplinary collaboration of diagnosing, treating and habilitating CP we need an external medium that can construct a shared, emergent, and socially-negotiated conceptual space. The written media have difficulties playing this role, due to the individual disciplines’ difference in specialized terminologies, concepts, and datasets. Video documenting is therefore already being used as an observational and diagnostic medium for CP, where many highlight the use of software programs to increase the ‘objectivity’ of the video analysis (Adde et al. 2010; Borel et al. 2011; Harvey & Gorter 2011).

Embodied cognitive (EC) science is critical about such ‘observational and spectator stance’ in understanding cognition. In contrast, EC aims to make an interactive turn in cognitive science and develop a second-person study of cognition (Thompson 2001), which should include aspects of experiential and emotional engagement and dynamic and reciprocal interaction (de Bruin et al 2012, Schilback et al. 2013, Satne & Roepstorff 2015). Video (documentary) can play an important role in such second-person study of cognition, but to do so, we must refrain from seeing it as providing observational data about human behavior, interaction and engagement, which is in need of ‘objective’ validity.

Instead, we should understand video as a medium for the scientists to interact, engage and corroborate data. In contrast to the written medium, video introduces, as Roschelle (1998) points out, some unique potentials for science: 1) video enables the scientist to preserve audio-visual data of human behavior and interaction, such as voice, the use of voice (paralanguage), bodily and facial gestures, touch, eye gazing, mimicking, social context, etc. Video-documenting can therefore be used to avoid the problem of ‘what I say’ and ‘what I do’ that can occur in self-reports. 2) Repeated viewing of a specific scene, can lead to complex insights that cannot be gained from textual transcription of the same scene. 3) Video supports interpretations from many frames of analysis, and can be used as common medium for rich multidisciplinary analysis. 4) Video can be shared with the participants in it, so as to acquire the participants own perspective on his or her behavior (Roschelle 1998, 727-28).

The documentary in this experiment was therefore a medium for collaborating with neuroscientists, psychologists, philosophers, and researchers in bioinformatics and geogenetics, and for Nossell to go through a number of different scientific studies: from MR-scanning, DNA-testing and motion-capture to different social experiments. All of this is documented so as to present a complex picture of what it means to live with CP. When the director had finished editing relevant scenes of the documentary, they were presented at different international conferences and workshops in cognitive science, philosophy and childhood disability. In doing so, the data was opened up so as to acquire multidisciplinary interpretations and analysis. In a few

cases the documentary scenes were presented together with Nossell, in order to get his perspective on his experience of the situation the scene was showing.

Thus, during the process of making the documentary and after, the documentary became a medium for opening up data and creating an interdisciplinary research process of understanding together, with other scientists, professionals and Nossell, the complexity of living with CP.

In the documentary a large social experiment is also conducted by using the medium of theater, which was inspired by Neisser's proposal of studying social cognition in an engaged way by collaborating with theater profession (Neisser 1980). We won't go into the details here, (see Martiny et al. in progress)<sup>56</sup>, but the point is that there are unexploited resources in other media, documentary or theater, that can be beneficially used by scientists.

Scientists are not foreign to other media, since, for example, visual tools, such as pictures, graphs and visual imaging are used to show statistical relation, and depict atom models, DNA structures and brain scanning. In the EC literature, this use of visual tools can be described as the scientists *extending* their cognitive processes (Clark & Chalmers 1998), which can be done both in published journals, power-points and poster presentations, all as a way to reduce the complexity of the communicative process. It's communicatively more effective, if the person you are trying to communicate with can visually experience what you are talking about.

### 3.2. How to Communicate: Engaging Society

In mentioning communication above, we are primarily referring to communication by scientists or professionals working with CP. Ideas from the documentary project has also been published in relation to the debate of the WHO's "bio-psycho-social" model (see Martiny 2015). Nevertheless, the idea of opening up by using another media is also chosen, so that others outside academia can engage with the knowledge.

Sharing of knowledge in a way that it is understandable outside academia is especially important in the case of health science, since here it can be vital for persons living with a disease, disorder or disability. The case of biotech entrepreneur Hugh Rienhoff and his daughter Bea is a case in point (Rienhoff and Bea are part of our second experiment, see below). Bea was born with a congenital defect that resisted satisfactory diagnosis and since diagnosis remained elusive, Rienhoff bought secondhand DNA sequencing equipment and started to look for a diagnosis himself. He succeeded and through exome sequencing revealed that Bea's condition is genetic, not inherited, but originated by herself as a "*de novo*" mutation. The mutation lies in the transforming growth factor- $\beta$ 3 (*TGF- $\beta$ 3*) gene, and is related to pathways affected in Marfan and Loeys-Dietz syndromes (Reinhoff et al. 2013).

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<sup>56</sup> See chapter 9 in this Ph.D. dissertation.

This case is typically used to promote do-it-yourself (DIY) genetics, personalized genomics and citizen science, but Rienhoff acknowledges that his mission wasn't just to diagnose Bea, but in fact to empower others: "I'm interested in cases of altruists who, rather than hiding from genetics, are using the opportunity to be sort of social activists, working to raise consciousness and maybe raise money for diseases affecting their family and friends" (Maher 2007; see also Maher 2013).

The case of the Reinhoffs is exceptional and with some problematic aspects, since it might lead other parents down a wrong path, searching for treatment instead of providing the proper health care (Maher 2007). Nevertheless, the aim of empowering others is inspiring and was also part of Nossell's motivation for making the documentary about his life with CP. As it has already been emphasized in using 'peer and mutual support groups' for mental disorders, sharing life experiences with others can: 1) increase a person's understanding and acceptance of her situation and autonomy, by offering new worldviews and new ways to view oneself, and 2) provide role models for different coping strategies, alternative perspectives, and allow for vicarious learning, modeling, and enhancement of problem-solving skills (Davidson et al. 1999, 168).

The aim, however, was not only to use the documentary as a tool of empowerment for persons with CP and their family, friends, and colleagues, but in fact to use it as an empowering tool for going through challenges in life as such. In experiencing Nossell's struggle to understand what it means to live with CP, we might relate it to our own struggle of dealing with personal challenges. To evaluate whether the documentary were able to communicate its message broader than to CP, the director and the production team sat up a test-screening of 22 participants: 11 women and 11 men, between the age of 22-67, and where 1 had elementary school education, 4 high school education, and 16 further education after high school.

The participants answered a questionnaire about the film where both quantitative and qualitative answers were given. Relevant for our purpose is that when asked about which statements that characterized the film they mainly answered 'moving', 'relevant', 'inspiring', 'funny' and 'thought-provoking'. In answering which mood the documentary put them in, they answered: 'thoughtful', 'being moved', and 'entertained'. They described Nossell's overall goal as: 'to give reflections on what a good life is and should be', 'to be recognized as normal and able', 'to question abnormality', 'to acquire self-knowledge', 'to be accepted by himself and others' and 'to prove to himself and others that he has a right to live'. However, many participants raised questions and were unclear as to the role of Martiny in the documentary: 'why is Martiny in the documentary?', 'is Martiny an expert or an actor?', and 'was Martiny in charge of the science part of the documentary?'

We want to emphasize here is that whereas there are much potential, there are also problems in the collaboration between science and documentary. It seems that the scientifically inspired points are coming broadly across in the documentary, but the role of the scientist becomes unclear and distrustful, when engaging with different media than the written. Scientists are also known to have, and should have, concerns

about how they and their work are presented in the mass media (Suleski & Ibaraki 2010). In the second experiment we therefore wanted to discuss and develop collaboration in such open media further.

## 4. Collaboration – On the Edge of a New Paradigme?

The second experiment is the documentary called *Collaboration – On the Edge of a New Paradigme?* This documentary and experiment was directed by Birkegaard as a way to investigate the topic of collaboration by meeting with and interviewing some of the world's most prominent scientists that research in collaboration or do collaborative science – this includes Reinhoff the DIY scientist mentioned above. The documentary therefore presents interdisciplinary, legal, and practical insights on collaboration from scientists coming from the humanities, natural and technological sciences. The film was shown at the documentary festival CPH: DOX (7<sup>th</sup> and 11<sup>th</sup> October 2014), on Danish DR3 (8<sup>th</sup> of May 2015) and it's distributed through the use of creative commons, and can be seen here: [Collaboration](#)

The aim was to see if researchers without any prior schooling in documentary filming could use documentary as part of their research process. In this case it meant to use documentary in the process of investigating the topic of collaboration. The challenge was not just to understand what collaboration is, but in fact how to do it, and how to involve leading researchers and practitioners in the investigation process. The documentary experiment operates with two hypotheses: 1) documentary is a shared space for engaging people in practicing collaborative science, and 2) documentary is a way to engage with the collaborative resources of the internet in a meaningful and substantial way. This means that just as with the first experiment, this experiment deals with the challenge of both collaboration and communication, and shows the intrinsic interrelation between them.

### 4.1 How to Collaborate: A Question of Practical Knowledge

As mentioned above, collaboration is the main focus in OS, and even in traditional science, since it can increase our intellectual capacities to solve grand challenges. However, the problem isn't just to find scientists that are willing to collaborate, but to find those that have the necessary skills for doing so. On the one hand, as it has been highlighted in EC literature, the classical training in science opts for reflective 'I think' skills, which are specialized and decontextualized knowledge skills (Gallagher & Marcel 1999, see also Donaldson 1978). When we emphasize societal and grand challenges, these skills are not sufficient for collaboration. Over all, one cannot reduce the skills needed for collaboration to skills in joint publishing.

On the other hand, the collaborative skills needed should still be knowledge skills, so the aim is to not 'openwash' the knowledge processes. In their discussion of openmindedness, Metzinger and Windt precisely highlight that to be open minded is an epistemic practice of doing science in a different and new way. This is

not a theoretical position and especially not a strategic position in order to get further funding (Metzinger & Windt 2015, 23). It requires new science skills and thus new ways to educate scientists.

What are these practical and collaborative knowledge skills and how can they be taught? In the documentary, V. Cerf, one of the fathers of the internet, states that collaboration was essential for the birth of the internet (see also Leiner et al. 2009). He defines collaboration as “multiple people working on the same problem and exchanging ideas.” As we have already seen in the first experiment, the medium of documentary is a way to open up the knowledge processes in research and to create a joint problem space in which shared and collaborative engagement with different scientists becomes possible. In this experiment collaboration occurred in the actual situation of meeting with, interviewing and filming the scientists, and through the activity of showing the scientists their own as well as the interviews with other scientists.

A meeting and interview with H. Dreyfus, who has been one of the most prominent advocates of the Embodied Cognition (EC) movement, can be seen in the documentary. Here Dreyfus clarifies a fundamental point in EC, namely that knowledge processes are not about having the right rules in your mind, and not just about reflecting, thinking, memorizing or asking the question ‘why’. In EC one distinguishes between cognitive processes of ‘I think’ and of ‘I can’. The latter is a question of ‘how’ and of doing, which relies on experience, learning by taking risks and making mistakes. It’s an intuition where one dynamically interacts with the situation in order to gain knowledge (see also Dreyfus 1972, 1992).

In this respect the making of a documentary becomes relevant. Roschelle has argued that video is a beneficial method for data collection for educational and social science, since it enables the researcher to leave the laboratory settings and conduct fieldwork, where one can engage with one’s research topic in a contextualized way. In doing so, one should not rely solely on video data, but should instead utilize a triangulation of data of interviews, journals and observations (Roschelle 1998, 725). So, in addition to the interviews conducted in the documentary, the experiment also includes an observational study of a collaboration between the Danish biocompany *Novozymes* and the biohacker garage *Labitat*. The collaboration can be seen in the documentary, and was aimed at developing biological lab-equipment in an open way.

All in all, data and knowledge coming from the documenting, interviews and observation was a foundation for understanding the challenge of how to collaborate. Many different terms are used in EC to describe this ‘how’ form of knowledge, such as ‘practical’, ‘know how’, ‘experience’, and ‘tacit knowledge,’ all of which are typically difficult to conceptualize and verbalize. Nevertheless, one innovative contribution of EC has precisely been to describe this kind of knowledge, typically in so-called pre-reflective terms (Gallagher 2005; Gallagher & Zahavi 2008).

When it comes to collaboration it is this pre-reflective type of knowledge that is crucial to understand and embrace. As mentioned, the challenge of collaboration is not only that there is a lack of research incentives



for such practice, but also that collaboration requires the knowledge of how to collaborate. This knowledge is in the EC framework described in terms of ‘we can’, ‘we-agency’, and ‘we-experience’, none of which are specialized knowledge processes that ‘we think,’ but rather contextualized processes that ‘we do’.

In the documentary, D. Thomas, associate professor in communication, highlights the distinction between explicit and tacit knowledge, and emphasizes that “in the 21<sup>st</sup> century the tacit is becoming increasingly important.” This requires, according to Thomas, that our education of students changes from mechanistic learning - transferring specialized knowledge content from teacher to student - to education that focuses on contextualized, tacit (pre-reflective) and dynamical knowledge (see also Thomas & Brown 2011). Kraker et al. stress the challenge of communicating tacit knowledge (Kraker et al. 2011, 647), but in educational science and teaching, video has been, for a long time, used as a way to acquire such forms of knowledge (e.g. Sherin & van Es 2005). The use of video for educational purposes is already emphasized in online and virtual universities (Open Educational Resources), and is further exemplified in the growing use of YouTube tutorials for gaining specific skills or knowledge.

The tacit knowledge skills for collaboration are flourishing in many other places than solely in the science system. One solution to the challenge of collaboration is, therefore, to open up science, so that it is possible for necessary partners coming from outside academia to be actively included in the collaborative scientific processes. Such opening up for pragmatics in professions other than cognitive science has been the foundation of EC, and argued by Varela, who refers to professions such as education and learning, sports training, psychotherapy, and especially to the Buddhist practice of mindfulness meditation. However, he points out that integrating such pragmatics and taking such tacit knowledge serious

“can only happen when the entire community adjusts itself - with a corresponding change of attitude in relation to acceptable forms of argument, refereeing standards and editorial policies in major scientific journals - so that this added competence becomes an important dimension for a young researcher. To the long-standing tradition of objectivist science this sounds anathema, and it is. But this is not a betrayal of science: it is a necessary extension and complement...It requires us to leave behind a certain image of how science is done, and to question a style of training in science which is part of the very fabric of our cultural identity.” (Varela 1996, 347).

## **4.2 How to Communicate: Technology is Essentially Human**

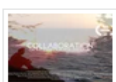
The advantages of the internet and the online tools are typically promoted by OS as a ‘game changer’ for doing science. OS scholars typically aim at combining open access with social media, which is the “fluid realm of websites, blogs, file sharing, and social networking: the dynamic, unmediated, uninhibited, and challenging domain of ‘Web 2.0’” (Grand et al. 2012, 683). But no matter how many tweets or blogs a

scientist might write, they would not have, and will never have, the potential of embracing the pre-reflective and tacit aspects of knowledge.

As Dewey emphasized: “There are values and meanings that can be expressed only by immediately visible and audible qualities, and to ask what they mean in the sense of something that can be put into words is to deny their distinctive existence” (Dewey 1987, 80). A way to rephrase Dewey’s point is to say that ‘a picture says more than a thousand words.’ This phrase is taken literally online, and Instagram, Snapchat and other apps have given people the possibility of saying a lot more than thousand words. In addition, Youtube is one of the most used online tools and an audio-visual media that is used for global communication.

Nevertheless, in the documentary, Thomas, rephrasing the German philosopher Heidegger, states that “the essence of technology is in no way anything technological, it’s people, it’s human, it’s communication.” (see also Heidegger 1977). In the EC literature communication is described as a collaborative process between humans, where “we are collaborators for each other in consummate reciprocity. Our perspectives merge into each other, and we co-exist through a common world” (Merleau-Ponty 1962, 413). It is through a reciprocal sharing that we engage in communicative acts and a common we-experience is established. Aspects, such as, of body language, gestures, mimicking, emotions, haptic engagement, context, etc. are highlighted as fundamental for this communicative and common sharing of a we-experience. These aspects are necessary for developing higher communicative potential, e.g. verbal language, and for grounding a universal and structural language that we humans are able to understand, despite differences in verbal language.

One of the reasons why the examples of Instagram, Snapchat and Youtube are so commonly used is precisely because, they share through pre-reflective processes, audio-visually displaying aspects of embodiment and situations. The meaning communicated through pictures or videos isn’t specialized for only a few, but transparent, immediate, universal and ultimately understandable. They are media for global social sharing. The aim in this experiment was to harness the potential of this global sharing in communicating the documentary and distributing, by using creative commons, the documentary on different platforms such as [documentaryheaven](http://documentaryheaven.com). As this article is being written, the documentary film has been downloaded 53.914 times, played 14.549 times and been seen in more than 150 countries (see figure 3).



## Collaboration - A documentary

Uploaded 3 months ago

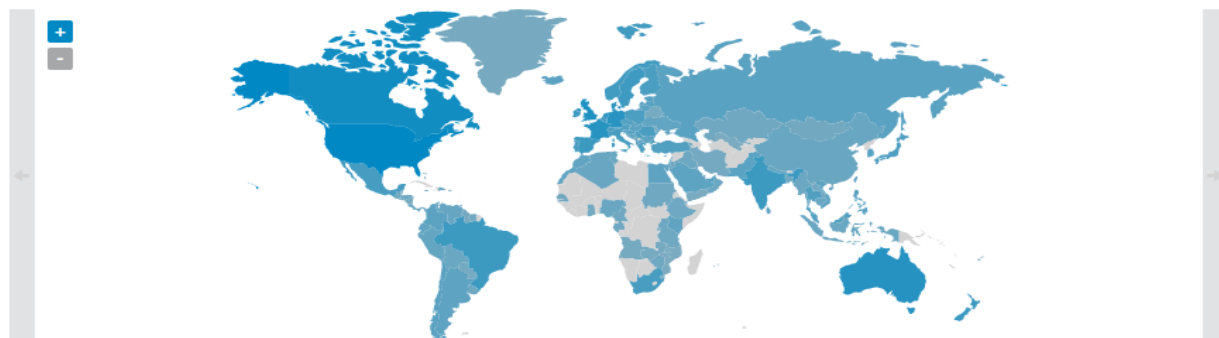
General

Embed

Geographic

Show past: **Week** / Month / Year / All-Time / Custom

Feb 9, 2015 – May 12, 2015



	Country	Total Loads	Total Plays
1	United States	13,886	4,050
2	Canada	7,509	1,970
3	United Kingdom	3,900	1,232
4	France	3,554	387
5	Australia	2,671	855
6	Germany	3,100	394
7	Denmark	1,722	557
8	Netherlands	1,620	428
9	Brazil	927	261
10	India	937	234

**Figure 3:** Illustrating the total of loads and plays of *Collaboration* in the top-ten countries and by color scheme going from minor (grey) to major (dark blue) loads and plays.

As with the first documentary, the question is, nevertheless, whether the knowledge communicated lives up to the standards for scientific knowledge. Collaborating with graduate students from the Roskilde University, a screening was conducted, where a focus group of 8 graduate students were interviewed about their experience of the documentary. The overall points of these interviews was that: 1) the documentary used visual techniques extensively, stealing the focus from the science being communicated, 2) the participants accepted a loss of knowledge about the topic in moving from text to the documentary and 3) the documentary can reach a broader audience and is more interesting and entertaining than written communication on the topic of collaboration.

As with the first documentary, there are both advantages and disadvantages in using documentary for communicating science. However, the aim of the experiment was to create a medium that was transparent and could engage people from both inside and outside academia. The success criteria was that the

documentary could be used for further discussions and knowledge productions on the topic of collaboration. In order to achieve this, the webpage [collaborativesociety.org](http://collaborativesociety.org) was created as a supplement to the documentary. Here people can access the more than 40 interviews that the documentary is based upon, and read up on the topic of collaboration. Therefore, the documentary should not be seen as an end result for understanding the topic of collaboration, but as point of departure for a dynamic process of further collaboration on the topic.

## 5. Conclusion: How to Cultivate a Public Multimedia Library of Science?

In the paper we have presented a proof-of-concept for open media, which should be seen as an addition and supplement to the already-established six open aspects of Methodology, Source, Data, Peer Review, Access and Educational Resources. By presenting and discussing two experiments in science and documentary collaboration we have argued that open media have the potential for dealing with the challenges of collaboration and communication. However, Rochelle has stated that a “research video is not like a research paper because a research video lacks a commonly understood genre” (Roschelle 1998, 723). To develop such genre is part of the last challenge of OS, the challenge of cultivation.

Scholars advocating OS are talking about cultivating a new collaborative mindset for doing science. This cultural change is the ‘hard problem’, since it is one of the minds of scientists. Changing a mindset into a collaborative one is not something that we can do strategically or by scientific reasoning. It’s something that relies on education, know how, something we do actively together, and it needs new systems of assessment that takes collaboration seriously. As we have pointed out above, this change requires that rather than understanding science as definitive experiments with polished results, we should see “science as a dynamic, tentative, uncertain, and constantly revised activity” (Grand et al. 2012, 681).

What does this mean for evaluation and validation of open media? First of all, it means a different way of understanding validation that disposes of the correspondence idea of objective truth, also called the representative idiom (Pickering 1995, 5). In embodied cognition, validation is instead described in social performative and pragmatic terms, highlighting “intersubjective validation” (Varela & Shear 1999, 10), “intersubjective corroboration” (Gallagher & Zahavi 2008, 29-31) and ‘performative consistency’ (Petitmengin & Bitbol 2009, see also Pickering, 1995). Knowledge is something that we create together and not something ‘to be dug up’.

How this type of validation would look like in relation to open media requires further development, but it emphasizes a second aspect, namely that evaluation should be seen as an *open-ended* process. As it has been argued in open data discussions, in addition to reproducibility, opening up data allows the evaluation of different hypotheses on the same dataset. The data can be reused and recycled, creating more dynamic

conclusions and knowledge (Murray-Rust 2008). As we have argued, it should not be scientists alone that can partake in such dynamic evaluation of data, but a broader public of creative, or simply curious, individuals.

Thirdly, it also means to reimagine the peer-review model, so that it is opened up for others and becomes a more open-ended process. One such model can be based on comment crowdsourcing and the use platforms of invited moderation, post-publication commenting, post-publication measures of quality and impact, and community-based review (Shashok 2010; Pickard 2012). In such review processes it would be more about "getting visible or vanish" than of "publish or perish" (Enzor 2012).

In this paper we have tried to take this notion of 'visibility' seriously and argued for open Mmedia in science. The idea of open media depends on further development, but the ideal aim is to open-mindedly start creating a dynamic, sharing and collaborating knowledge community in science.

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## Chapter 11

### Conclusion

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The main question of this dissertation was: *how do we help persons living with CP?* The aim wasn't to give a conclusive answer to this question, but to scratch at the surface in order to find some areas, primarily in relation to control and certainty, where we could intervene and help people to live with CP. In order to do so, another essential question needed to be answered: *what does it mean for a person to live with CP?* An all-encompassing understanding of CP was presented as a way to answer this question, which required that one broaden the current (anti)spasticity understanding of CP in order to take up a 'bio-psycho-social' perspective.

#### 1. Opening up Cognitive Science

As a point of departure, the dissertation turned to the embodied, embedded, enacted and extended approaches to cognition as a framework for investigating the biological, psychological and social aspects of living with CP. Two claims were endorsed, without explicit justification. The first was the claim that it's not sufficient to understand cognition in whatever neuronal, mental or computational terms that would restrict cognition to the skull. Mind, body and world should be seen as mutually dependent in an account of cognition. The second was the claim that, if we truly want to develop an embodied, enacted, embedded and extended cognitive science, we must acknowledge lived experiences as a constitutive part of cognition.

The justification of these claims in this dissertation should be seen as a primarily indirect and pragmatic matter that is related to the case of CP. This idea of justification focuses on the possibilities we acquire for the further development of cognitive science when we *embody* these claims in trying to investigate what it means to live with CP. As mentioned, the overall claim of *embodying cognition* is a pragmatic claim that, as cognitive scientists, 'we should do as we say.' If we argue that the mind is embodied, embedded, enacted and extended, we should, as minded scientists, be embodying these considerations in the method and ways of studying cognition. The overall point here is that, in cognitive science, we shouldn't only progress theoretically or have an interdisciplinary focus. We should also cultivate a new pragmatic mindset for doing cognitive science.

For the case of CP, this meant that we needed to 'open up' cognitive science so as to be able to engage and collaborate with persons with CP, with their relatives and with professionals that work with CP. In other words, it meant that, together, 'we can' understand what it means to live with CP. Here, meaning doesn't refer to what is meaningful within cognitive science, but to what is meaningful for persons with CP in their daily lives. Thus, in studying persons with CP, the question became more one of opening up one's research,

questions, methods and theory so as to be able to engage with them, see the relevance that such scientific knowledge might bear for them and, thereby, help them to live with CP.

The claim of embodying cognition was not founded as a strong methodological or normative claim meant to stress that this is the best way to conduct embodied cognitive science. Whether or not one should buy the claim of embodying cognition depends upon the topic of cognition one investigates, the kinds of problems one aims to solve and the answers one hopes to give. However, the aim in the dissertation was to understand what it means to live with CP in order to help persons with CP, so it required embodying the theoretical considerations in order to be able to engage with persons with CP.

The evaluation of the dissertation, of whether or not the three different claims presented above are justified, should be seen as two-fold and should consist in the success, efficacy, and functionality of how well the developed pragmatics adapts both to the world of CP and to that of embodied, enacted, embedded and extended cognitive science. This kind of evaluation is pragmatic in that it focuses on pinpointing the innovation, development and contribution that comes from this project within both worlds.

## **2. Relevance: Embodied Cognition**

In this dissertation, different initiatives have been set up that might be of relevance to the E-approaches to cognitive science. In the first, methodological part, I have argued for an overall change in the cultivation of cognitive science, that opens up cognitive science and includes pragmatic concerns (chapter 2). I have tried to show how this is possible in a second-person cognitive study of pathology that aims to engage with the persons that one is investigating. While the method for doing so, namely the phenomenological interview, is not a new, innovative idea or method in cognitive science the aim was to strengthen the idea and method in new ways so as to bring phenomenology and cognitive science closer together (chapter 3). I also presented a pilot-study of how to do more open experiments by using theatre performance and collaborating with theatre professionals. This was done as a way of opening up the lab of social cognitive science when doing second-person engaged studies of social cognition (chapter 9).

The actual case study of CP presented in chapters 4-7 might also be relevant to the E-approaches to cognitive science. Here, the case of CP was used to discuss and present new perspectives on issues such as the experience of disability (chapter 4), motor control and the sense of agency (chapter 5), the sense of control and bodily certainty (chapter 6), and cooperation and collaboration in the case of helping (chapter 7).

The third and final part of the dissertation might also be of relevance to the E-approaches insofar as it is more practical and pragmatic, as can be seen in chapter 8, where the aim was to take the first few steps towards developing an embodied based framework of therapy. In chapter 10, the notion of 'open media' was discussed so as to show how the E-approaches could incorporate an audio-visual medium into their way of

communicating science, as well as their way of doing science. This aim was therefore both practical in relation to science communication, and methodological in relation to opening up cognitive science.

Whether or not these initiatives are actually relevant to the E-approaches to cognition is not only a theoretical matter, but also a pragmatic issue of cultivation. Only time will tell. Nevertheless, the second leg of the evaluation of the dissertation refers not to the world of cognitive science, but to that of CP.

### 3. Relevance: Living with CP

The methodological development of cognitive science, of opening it up (chapter 2-3), was undertaken so as to be able to better understand, engage with, and ultimately help persons with CP. In part II, descriptions were given by both persons with and without CP in order to understand what it means to live with CP. The aim was to understand experiences of how persons with CP had learned to live with CP (chapter 4), so as to take those experiences as a point of departure and enhance them. To further investigate such experiences, the dissertation presented three different perspectives on the matter, each inspired by the ‘bio-psycho-social’ mode. The first was a neuro-physiological and computational (bio) perspective on motor control and the sense of agency that persons with CP experience (chapter 5), the second an experiential and psychological perspective on their sense of control and bodily certainty (chapter 6), and the third a social perspective on the way in which persons with CP are able to collaborate with strangers in situations in which they are in need of help (chapter 7).

Based on these theoretical insights, the aim in Part III was then to develop ways to help persons with CP. Chapter 8 presents one way to habilitate persons with CP by developing and discussing an embodied cognitive model of intervention that works with their experience of self-control. This was a pilot-study that, despite presenting positive results, was still limited to a few persons with CP. After this first pilot-study, the Helene Elsass Center has focused on such an embodied model of intervention in order to further develop it and, at the present moment, six more interventions have been held for children, adolescents and adults with CP. These interventions seem to be at least as successful as the first pilot-study.

In chapters 9 and 10, the focus was broadened from being directly aimed at persons with CP to include a more societal concern regarding, and social narrative about, what it means to live with CP. A theatre performance, *Humane Liquidation* (Human Afvikling in Danish), and a documentary film, *Natural Disorder*, both of which are about what it means to live with CP, were developed so as to be able to empower both persons with CP and their relatives, as well as people for whom such insights might be of relevance. The theatre performance seemed to be able to change the understanding that persons without CP had of persons with CP. The theatre performance will be playing for a longer period of time in 2016 in Denmark, whereas the documentary film will premiere October 7, 2015 in Denmark and will have its international premiere

afterwards. Thus, it's still uncertain as to how people with CP, their relatives, and others will react to the documentary film.

The question of how we can help persons living with CP is as complex and difficult to answer as any healthcare question. The aim of the dissertation has not been to give conclusive answer to this question. By integrating the different initiatives presented in the dissertation, especially in part III, I have only taken a few steps towards such an answer. I hope, nonetheless, that I have at least taken a few, and shown that, in order to answer the overall complex and challenging question of how to help persons with CP, there is only one way to walk. That's the way of opening up so as to collaborate.